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New Models of Care

Developing a Better Coordinated, High Quality System of Care for People with Disabilities

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Research report #: C-M-13-065

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and Recovery Research

*“It was like we’d landed on Mars
without any help whatsoever...”¹*

¹ Mother of a son with ABI

Project Number: C-M-13-065

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This report has been prepared by Prof Amrik Sohal, Prof Ian McLoughlin, Prof Fang Lee Cooke, A/Prof Daniel Prajogo, Dr Richard Cooney, Dr Candy Ying Lu, Ms Karthyeni Purushothaman, and Ms Sanaz Bayati Bojakhi. Other members of the research team were Dr Peter O'Neill and Prof Greg Bamber.

Submitted to: Gulsun Ali, ISCRR

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Abbreviations

ABI	Acquired Brain Injury
CP	Care Provider
EEO	Employment Equal Opportunity
HR	Human Resources
HRM	Human Resource Management
OH&S	Occupational Health and Safety
PSW	Paid Support Workers
SCI	Spinal Cord Injury
TBI	Traumatic Brain Injury

Executive Summary

TAC has embarked on a strategy to make its service delivery more client-centred in order to support independent living for people with traumatic brain injury (TBI) and spinal cord injuries (SCI) in Victoria. The objective is to improve performance in scheme viability, client experience and client outcomes. This pilot study was commissioned to scope options and possibilities for developing a better coordinated, high quality system of care to support these objectives through improvements in management and business processes in the delivery of services to clients - in particular with respect to key aspects of the service delivery model in relation to the management of human resources, service quality and continuous improvement, and the management and sharing of information.

The objectives of the pilot were:

- 1) To assess the implications for service delivery of the adoption of new therapies and care needs for people with TBI and SCI (e.g. care models based on building positive behaviours, independence and personal goal setting);
- 2) To assess, in the light of this, the current skills and competencies of care workers employed by three selected care organisations and identify future training and development requirements and workforce profile;
- 3) To identify the potential for the adoption of new service delivery models based on ideas such as, continuous improvement and service innovation intended to support more integrated and co-ordinated service delivery; and
- 4) To examine how digital and assistive technologies might best be designed and deployed to support such service improvement and innovation and client-centred care.

Our research covered both compensable and non-compensable sectors. Our findings suggests that the existing model of service delivery in the sector as a whole has the following characteristics many of which act as institutional and cultural barriers to developing a more client-centred approach able to support independent living, including that being attempted by TAC for its client base:

- Existing approaches to staff resourcing, skills, training and development, and work roles and environment with service providers acting as barriers and constraints to matching care support worker capabilities to client needs; improving the quality of care delivery, reducing risk and building workforce capacity; building a mobile team-based approach in the delivery of care and increasing commitment and job satisfaction amongst the care support workforce.
- Existing service models are fragmented and service providers find it difficult to see the client and their needs holistically and still tend towards a provider-centric view. This acts as a barrier and constraint to the degree of tailoring of care to specific client needs, responding to the differential needs of client groups and impacts on costs through duplication and waste of resources and contributes to sub-optimal client experiences and outcomes.

- There are limited resources and capabilities for improvement and innovation in service re-design and the use of information and other assistive technologies to deliver care. This contributes to poor coordination, limited feedback and understanding needs and requirements (e.g. of care support workers and clients and their networks) and constrains knowledge and information sharing by all those engaged in care delivery. All these act to limit the scope for addressing performance improvements by service providers through technology-assisted service innovations which would have beneficial impacts on TAC's strategic KPIs.

To address these issues we identify by way of recommendations a number of action research areas intended as interventions to co-design and co-produce improvements and innovations in service delivery. These would have the aim of identifying, trialling and evaluating key elements of a new service delivery model better able to support the innovations in care and physical environments at the heart of support client independence. These recommendations focus on specifying in more detail what is required for the development of a 'one stop' service model based on the principles of brokerage and intermediation allied to improvements in: the efficiency and effectiveness of the management of human resources, the management of quality and service improvement, and the management of information and deployment of assistive technologies, in what has been termed, "technology-assisted long-term care".² To some degree a form of brokerage arrangement in the form of 'top down' integration characterises the compensable sector at present and provides a basis upon which such a service model might be evolved by combining this with possibilities for more 'bottom up' integration.

² Rossi Mori, A., Dandi, R., Mazzeo, M. and Verbicaro, R. (2012). Technological Solutions Potentially Influencing the Future of Long-Term Care (July 20, 2012). ENEPRI Research Report No. 114. Available at SSRN: <http://ssrn.com/abstract=2117750>

1. Introduction

1.1. Background

The above quote is from a client family member. They happen to be a client in the non-compensable sector. Acquired Traumatic brain injury (TBI) and spinal cord injury (SCI) are enervating injuries that have long-term impact on the injured person.³ Regardless of the circumstances in which such injuries are acquired – such as in roads or in the workplace – they inevitably place clients and their families in a totally unfamiliar and unexpected environment characterised by great uncertainty, emotional upheaval and challenges of life-changing gravity. How care services are provided, the skills and capabilities of those who provide them and the tools and resources available to assist them and co-ordinate their efforts have a major bearing on the experience of clients and their families in coming to terms with their injuries and the outcomes of care in the long-term. The management, organisation and innovative capacity of the care system as a whole - including the compensable sector in which the TAC scheme and its clients are located - are critical determinants of the viability of the service models used to assess entitlements, identify client needs, allocate resources, publish service offers, deliver care plans and evaluate overall effectiveness.

As a major cause of death and disability worldwide, TBI can result in significant and lifelong physical, cognitive, emotional, behavioural, and social function impairments. The Australian Institute of Health and Welfare has reported a rate of 107 TBIs per 100,000 population in Australia, with many challenges involving long-term rehabilitation.⁴ In Victoria, there were 31,211 people admitted to hospitals for TBI during the five-year period from July 2007 to June 2012. Falls and transport accidents are the leading causes of TBI, accounting for 44% and 31% of hospitalisations, respectively. Most studies suggest that approximately 20% of TBI patients admitted to hospital have sustained moderate or severe head injuries, with the other 80% having mild injuries. According to one study, 'lifetime costs per incident case of moderate and severe TBI in Victoria have been estimated to be \$2.6 million and \$5.0 million, respectively'.⁵

Similar to TBI, SCI can cause lifelong physical disability and adversely impact on the quality of life. There were 1,015 people admitted to hospitals in Victoria with SCI during the five-year period from July 2007 to June 2012. The leading causes of SCI are transport accidents (43%) and falls (41%). Patients with SCI tend to have lengthy hospitalisations, for example, overall SCI patients have a median length of stay in hospital of 133 days. The lifetime costs per incident case of SCI in Victoria have been estimated to be \$4.9 million and \$7.6 million for paraplegia and quadriplegia respectively.

³ Access Economics Pty Limited. (2009). The economic cost of spinal cord injury and traumatic brain injury in Australia: Access Economics Pty Limited.

⁴ Ponsford, J. (2012). Understanding and managing traumatic brain injury. *InPsych*, April, <http://www.psychology.org.au/publications/inpsych/2012/april/ponsford/>.

⁵ Prang, K.-H., Ruseckaite, R., & Collie, A. (2012). Healthcare and disability service utilization in the 5-year period following transport-related traumatic brain injury. *Brain Injury*, 26(13-14), 1611-1620.

1.2. Aims and Objectives

This pilot study was designed to scope the work necessary in developing a better co-ordinated, high quality system for delivering care to people with disabilities – in other words a system that would be client-centred, flexible, responsive, and cost effective. Such a system would also make the most appropriate use of digital and assistive technologies in the context of other improvements and innovations in the content of care itself and in the architectural design of physical living environments including the retro-fitting of existing dwellings. The objectives of the pilot were:

- To assess the implications for service delivery of the adoption of new therapies and care needs for people with TBI and SCI (e.g. care models based on building positive behaviours, independence and personal goal setting);
- To assess, in the light of this, the current skills and competencies of care workers employed by three selected care organisations and identify future training and development requirements and workforce profile;
- To identify the potential for the adoption of new service delivery models based on certain concepts such as, continuous improvement and service innovation intended to support more integrated and co-ordinated service delivery; and
- To examine how digital and assistive technologies might best be designed and deployed to support such service improvement and innovation and client-centred care.

Our overall aim is that the findings and recommendations from this study can contribute to the development of a larger proposal, an element of which would be the establishment of a 'co-design space' for cross-disciplinary participative research to develop, test, trial and evaluate with stakeholders (clients, their support networks, care providers etc.) the options for new service models and their contribution, alongside innovations in care and physical environments, to achieving TAC long-term strategic objectives and improving KPIs.

It should be noted that the scope of our enquiries covered both compensable and non-compensable sectors since we aimed to get an understanding of these issues at the level of the care system as a whole and to situate more clearly and be able to differentiate where possible factors specific to the provision of services to TAC clients. The rationale for this was that service delivery, as opposed to service resourcing and commissioning, is common (similar or almost identical) to both compensable and non-compensable sectors with service providers using a common paid workforce, business processes and supporting systems to service clients from both sectors.

2. Research Questions

It is now widely accepted that service delivery should be client-focused or client-centred in order to improve understanding of client needs and in matching services to their specific requirements. Consequently, this change creates new imperatives in terms of the competencies and future profile of the paid care workforce. Over the past decades, the policy framework in the disability services sector has generally shifted from a benevolence focus to a rights-based approach, which provides for the full inclusion of people with disability in communities and the broad society.⁶ This approach promotes an ongoing improvement of the quality of services provided, with a focus on improving outcomes for people who use these services to create conditions that enable them to live independently, if desired.

The National Disability Insurance Scheme (NDIS) has given long awaited recognition at the national level to the need to enhance the independence, overall wellbeing, and quality of life of people with disabilities and in assisting family members and other unpaid carers such as family carers and volunteers.⁷ The NDIS is viewed by many as the means through which the experience of many people with disabilities and their family members can be radically improved and transformed. One insight into the overall experience at present is provided by the report, *Shut Out*, prepared by National People with Disabilities and Carer Council.⁸ According to the report, more than half of the respondents felt that services and programs received from disability service providers act as a barrier to, rather than a facilitator of, their participation in the service system, and that the service system is fragmented and fundamentally flawed, requiring a paradigm shift to deliver lasting change and better co-ordinated services.

The changes underway are also reflected in the type of care delivered and the philosophies which underlay them. For example, people with TBI and SCI usually suffer from physical, cognitive and emotional impairments, and a range of psychiatric symptoms such as depression, anxiety disorders, mood disorders and/or panic disorders.⁹ For a long time, the care and rehabilitation provided for persons with TBI and SCI predominantly focused upon their physical and cognitive disabilities. More client-centred approaches have shifted the emphasis to include assessment and treatment of psychological, emotional and social conditions. This has also been

⁶ Fattore, T., Evesson, J., Moensted, M., & Jakubauskas, M. (2010). *An examination of workforce capacity issues in the disability services workforce: increasing workforce capacity*. Unpublished final report: Community Services and Health Industry Skills Council.

⁷ Cortis, N., Meagher, G., Chan, S., Davidson, B., & Fattore, T. (2013). *Building an Industry of Choice: Service Quality, Workforce Capacity and Consumer-Centred Funding in Disability Care*. Sydney: Social Policy Research Centre, the University of New South Wales.

⁸ NPDDC (National People with Disabilities and Carer Council). (2009). *SHUT OUT: The experience of people with disabilities and their families in Australia* (Vol. National Disability Strategy Consultation Report). Canberra: Commonwealth of Australia.

⁹ Chan, J., Parmenter, T., & Stancliffe, R. (2009). The impact of traumatic brain injury on the mental health outcomes of individuals and their family carers. *Australian e-Journal for the Advancement of Mental Health*, 8(2), 155-164.

accompanied by an interest in the adoption of new therapies based on building positive behaviors, independence and personal goal setting.¹⁰

Service providers are now operating in a policy and care environment which has and will continue to be subject to significant change as client-centred approaches are applied to improve client experience and outcomes, whilst at the same time ensuring services are delivered in a cost-effective manner. Our first research question sought to explore how service providers perceived these changes and their implications:

RQ1. How do care providers, clients etc. view the changing context of care (e.g the move towards client-centred care, independence, self-direction and personal budgeting) and its likely developments and impacts on the sector in the next five years?

The competencies and capabilities of the paid support workforce are one of the main determinants of the quality of care provided to clients. In the context of client-centred approaches and broader concepts of the range of care required, the development of the skills and competencies and the overall professionalisation of the workforce have been identified in numerous studies as central to ensuring that care services are delivered to the standards intended by policy-makers and service commissioners and expected by clients and their families. Our second research question sought to explore the perception amongst service providers of the challenges involved in terms of the current skills and profile of the paid support workforce and how any skill gaps might be addressed:

RQ2. What are the existing skills and competencies amongst the paid care workforce? In the light of the new developments of care models, what are the major skill gaps as perceived by care providers? And what implications may these have for future training and development requirements and workforce profile?

The aim of better coordinated, more integrated and more 'joined-up' delivery of health and social care services, in particular to vulnerable groups and those with chronic conditions, is a widely articulated policy objective and is often related to ideas of more client-centred, self-directed and individualised service delivery models. Such an approach to service delivery is also seen as essential to confront the rising costs and demands on health and social care systems arising in particular from changing demographics, the increase in the incidence of chronic conditions and social and policy imperatives to address the issues faced by vulnerable groups such as those with disabilities. However, there is a large body of research conducted in many countries which indicates that there are many barriers – in particular institutional, organisational and cultural – to achieving such outcomes.^{11,12,13,14} This

¹⁰ Ylvisaker, M., Feeney, T., & Capo, M. (2007). Long-Term community supports for individuals with co-occurring disabilities after traumatic brain injury: cost effectiveness and project-based intervention. *Brain Impairment*, 8(3), 276-292.

¹¹ Baker GR, Denis J-L (2011). *A comparative study of three transformative healthcare systems: lessons for Canada*. Ottawa, Canada: Canadian Health Services Research Foundation.

¹² Curry, N. & Ham, C. (2010). *Clinical and service integration: The route to improved outcomes*. London: The King's Fund.

¹³ Cumming, J. (2011). Integrated care in New Zealand. *International Journal of Integrated Care*, 11(Special 10th Anniversary Edition), Oct-Dec.

has been identified as a particular problem in the Australian health and social care system. For example, it has been argued that services have traditionally been designed and delivered through policy program silos, with the consequence of creating 'one too many' contact points for clients. As a result, 'the very people that the services are intended for do not receive the assistance to which they are entitled and need'.¹⁵ Our third research question therefore sought to identify the scope for developing new models of service delivery:

RQ3. What new service delivery models might be appropriate in this sector for the future and how should these be developed and implemented?

In the quest to deliver better co-ordinated, high-quality, cost-effective care services, digital and assistive technologies have frequently been identified by policy-makers and others as a key enabler.¹⁶ Assistive technologies can be defined as 'any item, piece of equipment, product or system that is used to increase, maintain or improve the functional capabilities and independence of people with cognitive, physical or communication difficulties (e.g. 'low-tech' mobility devices such as a walking stick through to 'high-tech' speech synthesizers or stair-climbing wheelchairs).¹⁷ These largely 'stand-alone' technologies can be used not only to support people to maintain their independence, but also to redesign the way in which many aspects of disability care services are delivered. The UK Audit Commission identifies two types of digital technology which can support independent living. The first are tele-health technologies which enable a clinical process to be conducted remotely. The second is tele-care technologies (sometimes embedded in 'smart-housing') which allow vulnerable groups such as the elderly and physically less able to remain living in their own homes for longer. A major study by the Centre of European Policy Studies predicts that appropriate technology-assisted innovations will improve the economic sustainability of the long-term care industry as a whole.¹⁸

Such technologies have enormous potential to support independent living and improve service co-ordination through, for example allowing more timely and accurate sharing of information during the care pathway, supporting people with disability in self-directing their care, and in service commissioners in targeting resources and evaluating the effectiveness of policies and strategies. However, there is evidence, in particular in relation to older people, of a low investment, tack-up and use of assistive technologies which are often perceived as not meeting clients' needs. It is unlikely that the picture for those with disabilities is significantly different. By the same token, attempts to deploy tele-care and information technologies to bring about more service co-ordination in health and social care for the population at large as

¹⁴ The King's Fund (2011). A report to the Department of Health and the NHS Future Forum from the King's Fund and Nuffield Trust, *Integrated care for patients and populations: Improving outcomes by working together*, London; Nuffield Trust.

¹⁵ Bridge, C. (2012). Citizen centric service in the Australian department of human services: The department's experience in engaging the community in co-design of government service delivery and developments in EGovernment services, *The Australian Journal of Public Administration*, 71(2), 167–177.

¹⁶ Hwang, J., & Christensen, C. M. (2008). Disruptive innovation in health care delivery: a framework for business-model innovation. *Health Affairs*, 27(5), 1329-1335.

¹⁷ Audit Commission. (2004). Assistive Technology. UK

¹⁸ Rossi Mori, A., Dandi, R., Mazzeo, M. and Verbicaro, R. (2012). Technological Solutions Potentially Influencing the Future of Long-Term Care (July 20, 2012). ENEPRI Research Report No. 114. Available at SSRN: <http://ssrn.com/abstract=2117750>

well as more vulnerable groups have proved highly problematic. Our fourth research question addresses these issues, in particular in relation to the potential of finding ways of deploying enabling technologies in a manner which better meets client and service provider needs.

RQ4. How can service design tools and approaches (e.g. co-design/co-production) be adapted/developed to facilitate the delivery of client-centred care by specifying how digital and assistive technologies can best be deployed to better support such service innovation and client needs?

The next section describes our research methodology.

3. Methodology

3.1. Research Design

We have used a multiple-case design and followed the logic of replication for the purpose of analytically generalising findings and identifying research gaps.¹⁹ In order to understand the existing models of service delivery and the problems and challenges faced, our research focused on collecting primary data from three Victorian Care Provider (CP) organisations involving interviews and focus groups with managers and paid support workers plus a small number of clients/families.

To understand the overall system of care service delivery as it effects the care pathway of clients, we conducted interviews with a range of stakeholders outside of the CP organisations. To understand the commissioning and financing context in which the CP organisations operated, we conducted interviews with personnel at Transport Accident Commission (TAC) and the Department of Human Services (DHS). To gain further insight into the client experience, we visited two special purpose institutional homes which provided live-in facilities for both permanent and respite clients. In order to understand the issues in service co-ordination at a sub-regional level and at the interface between health and social care, we also conducted focus group discussions with managers representing regional alliance agencies (G21 and Barwon Health), TAC and DHS.

In addition, secondary data was gathered from the extensive policy, grey and academic literatures, primarily with a focus on Australia but also with a view to identifying best practice overseas in comparable settings. We also spoke with academic experts in the field.

The research was conducted between March and June 2013. An overview of the research design is given in Figure 3.1.

¹⁹ Yin, R. K. (2009). *Case study research: design and methods* (4th ed.). Thousand Oaks: Sage Publications.

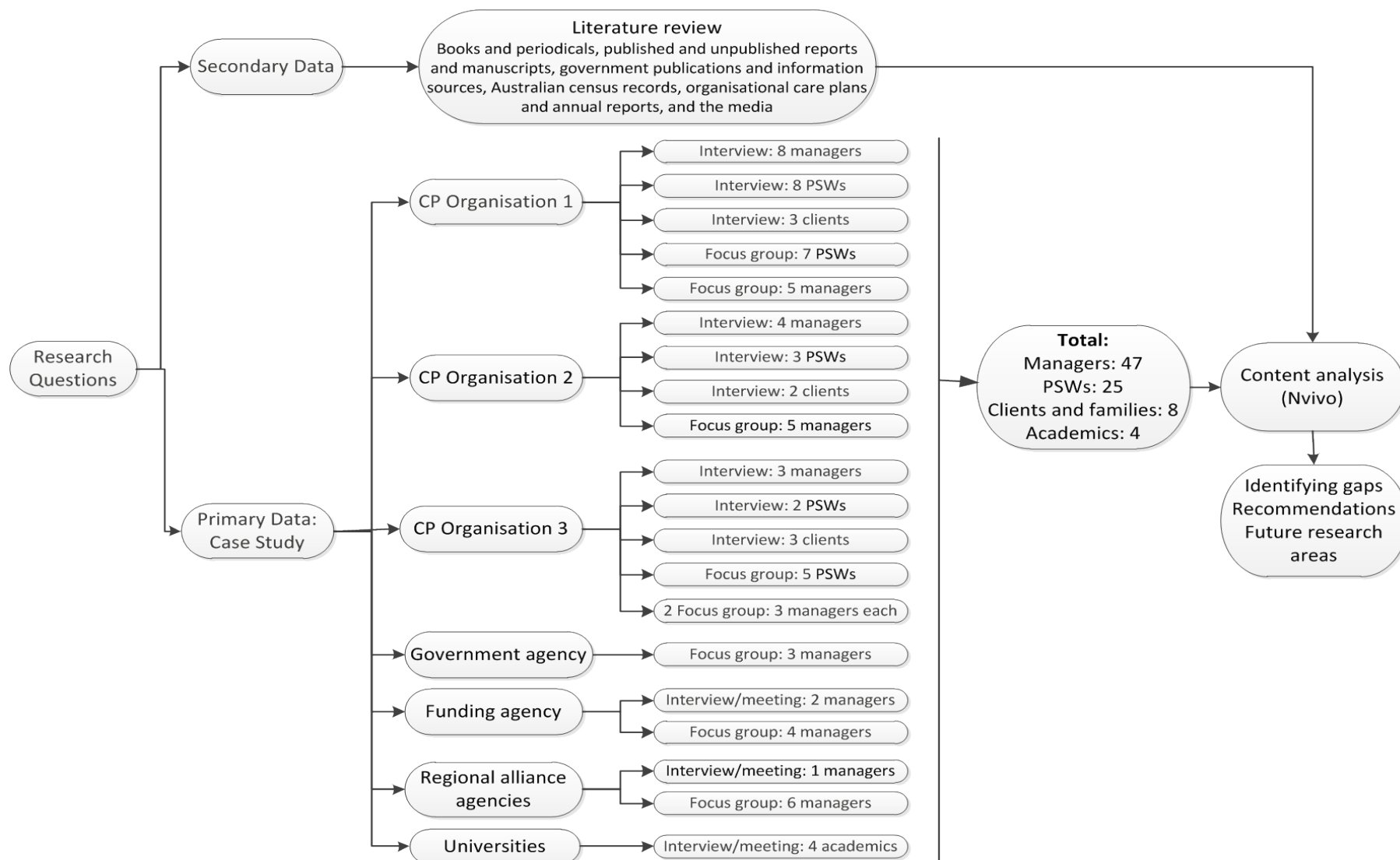


Figure 3.1: Overview of Research Design

3.2 Case Study Organisations

All three organisations were relatively large employers for the sector with well established - in one case for over 25 years history of operations in Victoria. There were chosen on advice from ISCRR as likely to be sources of data appropriate for our pilot research questions. Services were provided in particular, but not exclusively, for the disability sector and within the sector for both compensable and non-compensable clients. In each CP the TAC was a major if not the major commissioner of services. However, services were also provided under contract for other commissioners most notably the Victorian Department of Human Services (DHS).

Summary profiles of the CP organisations are presented in Table 3.1.

Table 3.1: Case Study Organisations

No.	Case Study Organisation	Employees	No. of Clients	Percentage of TAC-funded clients	Services
1	CP1	800-900	600	About 20%	Disability services
2	CP2	Over 1800	Not available	Not available	Disability, early childhood, aged care services and etc.
3	CP3	Over 1500	Not available	Not available	Disability, mental health, frail aged services and etc.

Note: the number of employees includes employees from all sites in Victoria and includes PSWs.

Within each of the three service providers we collected data through semi-structured interviews, focus groups and from analysis of documents provided by the CP. Semi-structured interviews were conducted with managers and direct paid support workers with whom we also conducted focus groups. In order to understand the perspective of those to whom services were provided, we also conducted interviews with clients and/or family members of clients (see below).

3.3 Sampling Strategy

Consistent with the scoping intentions and pilot status of our enquiry, respondents were selected for interviews and the focus groups through convenience and snow-ball sampling methods. To ensure an appropriate cross-section of views we sought to interview managers at different levels, including senior level managers and executives, middle level managers, and line managers, in each CP. Job titles of those interviewed typically included 'CEO', 'general manager', 'state manager', 'service delivery manager', 'OHS manager', 'HR manager', 'service coordinator', and 'PSW team leader'.

In total, we interviewed 15 managers. We also conducted 4 focus group discussions with 15 managers from the three CP organisations, most of whom being different to those interviewed. The sample had a varied but in most cases extended experience within the CP organisation they worked for and/or the disability sector as a whole. Among the respondents, 10 (43.5%) were males and 13 (56.5%) were females. On average respondents had worked in the disability sector for at least 8 years. Before

working in the disability care industry, many respondents had worked in the health care sector. All of the managerial participants possessed a tertiary qualification.

In addition we interviewed 13 PSWs across the three CP organisations and conducted 2 focus group discussions with 12 PSWs from two out of three of the CP organisations. In all cases focus group members were different individuals to those interviewed. Among those PSW participants, only 3 were males. The mean age of the PSWs was 39 years, of which 26.6% aged between 20-24, 26.7% aged between 25-29, 7% aged between 35-39, 13% aged between 40-44 and 26.7% aged 40 and over. Their mean organisational tenure was 3 years (the longest was 17 years).

Most of the PSWs had a tertiary qualification. A majority (47%) had a Diploma or Advanced Diploma and the study areas were mainly Community Welfare, Ministry, and Children Services. About 29% of the PSWs had a bachelor degree in the fields of Nursing, Paramedic, Youth Work and Psychology. About 12% had Certificate IV (mainly in the areas of Disability and Nursing) as their highest education qualification. Besides, 2 PSWs finished high school and secondary school education and did not have a tertiary qualification. A majority of the PSWs respondents were under permanent part-time contract, and only two working under permanent full-time contract.

In order to provide some context and understanding of their experience of the care provided by the SP and PSWs we also conducted interviews with 8 clients/family members. The clients/families were drawn more or less equally from the compensable and non-compensable sectors so that we could identify and contextualise the specific experience of TAC clients of service provision. It should also be noted that we faced several difficulties particularly in collecting data from clients with cognitive impairments and limited capacity to engage verbally. Within our sample this turned out to be more of a difficulty in the case of the TAC clients. Time and access constraints limited our ability to address this issue by broadening the sample and this could be an objective of a larger study which would have more time and resource to address the issues of method and methodology.

Consistent with the pilot status of the project, the insights gained from a convenience sample can only be regarded as indicative of the more general picture across the sector at state level and beyond. In no way therefore are the findings offered as being representative of more general views and perceptions of managers, PSWs or clients beyond the boundaries of the CP organisations concerned. It is also the case that the time frames within which this pilot has had to be completed have meant that it has not been possible to engage in a process of respondent validation to check the validity and reliability of our data to the degree normally preferred in qualitative research.

A breakdown of the numbers of interviews and focus groups conducted in each of the CP organisations is presented in Table 3.2. The coding scheme used to ensure participants remain anonymous is provided in Appendix I.

Table 3.2: Interviews and Focus Groups by Case Study Organisation

No.	Case Study Organisation	Number of Interviewees		Number of Focus Groups	
1	CP1	19	8 managers, 8 support workers and 3 clients/family members	2	7 support workers and 5 managers
2	CP2	9	4 managers, 3 support workers and 2 clients/family members	1	4 managers
3	CP3	8	3 managers, 2 support workers and 3 clients/family members	3	5 support workers and 6 managers
4	Government agency	-	-	1	3 manager
5	Funding agency	1	Meeting with 2 managers	1	4 managers
6	Regional alliance agencies	1	Meeting with 1 manager	1	6 managers
7	Universities	4	Meeting with 4 academics	-	

3.4 Data Collection Technique and Procedures

A majority of the semi-structured interviews were conducted through face-to-face depth interviews on the CPs' premises. Three interviews with PSWs were conducted by telephone. Depth interviews are a favoured technique in qualitative research, especially in exploratory studies, as they allow the researcher to adapt questions, seek clarifications and interpretations, ensure understanding and to probe issues and topics including those raised by the interviewee themselves.²⁰ Each interview was conducted in English and ranged from 45 minutes to one and a half hours in length.

To conduct the focus groups a facilitator from the research team guided the group through the discussion and kept the group focused on the topics listed in the discussion guide. The focus groups typically lasted from 60 to 90 minutes and were conducted on the CPs' premises.

All interviews and focus groups (where consent was given) were audio-recorded. Recordings were transcribed by a third-party transcription service organisation under an established confidentiality agreement with Monash University. Researchers also kept their own field notes during interviews, focus groups and site visits.

3.5 Interview and Focus Group Discussion Guide

The interviews and focus groups were based on a guide to questions that were to be explored to enable information to be elicited relevant to our four research questions and to provide appropriate back ground and supplementary information to permit interpretation. Consistent with seme-structured depth method all interviews were

²⁰ Cavana, R. Y., Delahaye, B. L., & Sekaran, U. (2001). *Applied business research: qualitative and quantitative methods*. Milton, Qld: John Wily & Sons Australia.

carried out in a nondirective manner. The interview guides for managers, PSWs and clients, and the guide for the PSW focus groups, is provided in Appendices II to V.

3.6. Data Analysis

Researcher field notes were compared with the transcripts of audio-recordings to identify redundancies, check for reliability, identify emerging themes and develop a schema for organising and categorising the data. Qualitative data analysis software was then used to search for data to confirm categories, and begin pattern-matching and explanation-building using analytical templates developed from the research questions.²¹ The themes coded included service providers and clients' views of the changing context of disability care; the paid workforce issues in the care providers; current service delivery models and challenges posed on developing new, client-centred care delivery models; and service innovation and technology implementation.

3.7 Ethics and Confidentiality

The research was subject to approval by the Monash University Human Research Ethics Committee (MUHREC). Ethics clearance for the research was received MUHREC on 30 April 2013. The approval was granted based on the submission of the study objectives, final interview guide and focus group discussion guide, and cover letters. All CP organisations have had their identity concealed and all respondents have been anonymised.

In keeping with the main issues of ethics and confidentiality, the research engaged only those respondents who indicated their willingness to participate voluntarily. At the beginning of each interview, the researcher explained the purpose of interview to the respondent and assured him/her that all information provided was strictly confidential, that he/she did not have to answer any questions he/she did not feel comfortable answering, that he/she could seek clarification or an explanation of any questions he/she had trouble understanding and that he/she was free to withdraw their participation at any time. Consent was then sought to audio-record the interview for transcription purposes. To reduce threat, the audio-record stopped whenever the interviewee asked.

²¹ Tharenou, P., Donohue, R., & Cooper, B. (2007). *Management research methods*. New York: Cambridge University Press.

4. Results

This section reports the findings from our interviews and focus groups conducted mainly within service providers but also with clients served by these providers. Although this report is concerned with the implications of client-centered care for service delivery as it effects client experience, outcomes and TAC scheme viability, managers and PSWs did not always find it easy to differentiate the compensable from the non-compensable sectors in their answers, comments and perceptions. Largely this seemed due to the fact that the paid workers, business processes and supporting systems used to deliver support were identical with no differentiation made with regard to how the client's services were commissioned or resourced. The client's and families interviewed did not of course struggle in making such differentiations themselves and we indicate clearly whether observations made when considering their views are from TAC or non-compensable clients.

4.1. Service Provider, PSW and Client Views of the Changing Context of Disability Care

Overall the findings from the pilot study indicate a cautious response to the fundamental changes now in prospect in the disability care sector as a whole. For example a manager from a service provider organisation was apprehensive about the NDIS: *"...you worry about the NDIS when it kicks in and you don't know how it's going to be in terms of the distribution of the funding really...Right now I think ... Disability Care Australia - it's the great unknown...We just don't know what that means for us or for the sector."*(M3-3)

Some service providers noted that many aspects of self-direction and client engagement with budgeting are already evident in the compensable sector and that therefore the impact would not be so great compared to the implications for those in the non-compensable sector.

The general mood expressed in our focus groups, both with the paid support workforce (echoed by those with clients and their support networks – see below), was one of underlying uncertainty as to how the rollout of NDIS would affect both the compensable and non-compensable sector, the care provided and the way that services will be delivered. As one PSW put it: *"I think it's come out now, they are all saying 'NDIS is good, good, good' but what is good?"* (C2-2)

Client Views:

As might be anticipated it was clients in the non-compensable sector who had the keenest interest in the implications of the NDIS. As one client put it: *"...I'll be keeping a very close eye on things [on the NDIS]. And hopefully it'll all come true."* (CL3-2) Similarly, a retired father of a client with ABI from the non-compensable sector whose daughter was in a vegetative condition in a care-facility described his anxiety about the current care model. He is more hopeful that his daughter will be cared for after his own demise if the NDIS was in place. He cited the huge cost and burden that his family had to bear in addressing his daughter's treatment and life-long care. His family has had to find huge amounts of money to buy her a special bed recommended by her physio-team, a customised vehicle to transport her and a host of other related expenses. This father's major concern is who will take care of his

daughter when they (he and his wife) pass away: “...So *that’s why we’re really big advocates for the Disability Care Australia so we’ve been campaign champs with NDIS for a long, long time.... We’ve been campaign champs for that right from the start so that everybody’s equal.*” (CF3-1)

Appendix VI provides further views on the changing context of care.

4.2. The Paid Support Workforce

The findings from our interviews with managers and PSW’s in the service providers revealed three major issues in relation to the paid support workforce:

- Problems of staff resourcing
- Gaps in skills, training and workforce development
- Problematic experience of work roles and environment

These are described further below.

4.2.1. Staff Resourcing

Our findings indicate that care providers perceive significant challenges in recruiting, deploying, and retaining a paid support workforce of sufficient quantity and quality to deliver care to TAC contract requirements. The issues identified by managers and PSWs included:

➤ Recruitment

- It is well documented that the care sector is experiencing significant problems in relation to skill shortages and not surprisingly that each of the three care providers find that it is hard to attract highly competent Paid Support Workers (PSWs). For example, a manager said, “...*there are so many inherent problems with what is a very under resourced field and can lack in certain quality as well. It’s a constant battle getting good staff. So there doesn’t seem to be any real solution to it.*” (M1-4)
- Care providers do not have an abundance of staff resources at their disposal, and there are pressures to compromise on skills, competencies and experience when recruiting new staff. This was emphasized by a manager: “*If you read some of the complaints underlying tones are about capability, about staff capability ... if you’re a higher level, tertiary level of course you have to pay more. So we recruit not necessarily at a high knowledge base, for example*” (M2-1)
- Managers acknowledged that there were many problems in their recruitment practices. For example, sometimes recruitment is *ad hoc* rather than being targeted at required skills and competencies of the position. As a result, many new recruits do not have the relevant capability required in this industry. For example, a manager explained, “...*we are recruiting, although we say we recruit from value space, we don’t often recruit very targeted recruitment, like that is fit for purpose ... we do a mass kind of recruitment and it’s not fit for purpose. Whereas in the past when I recruited I recruit fit for purpose. It costs more, it’s time consuming, but I prefer you spend more time at the starting point*”

and then later on find out all the workforce issues and problems and complaints and incidents that it's just not good." (M2-1)

➤ *Deployment of skills*

- The match between client care needs and the experience of PSWs is seen to be *ad hoc* by both care providers and workers and is not regarded as based on a systematic matching of client needs with the capabilities and skills of the PSWs. When a manager was asked whether they match PSWs skills, knowledge and experience with a particular type of clients, she replied: *"It depends. If somebody moves into a house that already has a group of staff, they get what's there ... Plus the fact a group situation where you've got a residence with five or six clients, they can't have everybody that suits them. Somebody might be somebody else's favourite or preferred person. So that happens."* (M2-3)
- Many PSWs believe that the mismatch between their skills and client needs is a major issue and one with a significant bearing on service quality and client satisfaction. For example, a PSW said, *"I don't think there's enough resource for support workers to assist clients with that trouble. I don't think that the clients that they are matched up with are necessarily appropriate."* (C1-4)
- PSWs say scheduling is a major issue in some organisations. Some PSWs felt they are not respected because the scheduling of work appears to them to be random and sometimes the care provider changes the roster without informing them. For example, a PSW complained issues of scheduling, *"... [CP-3] rang me yesterday, 'Oh Hi ... I was wondering if you would do a six to ten shift tonight if I can cover your other shift?'. And I said, 'Yeah, okay'. 'Oh that's good, because we've already covered your other shift'. So they'd covered that shift even before they rang me."* (C3-2)

➤ *Workforce turnover*

- Managers in all of the care providers stressed that they are under some degree of financial pressure and that staff in the sector are underpaid. The PSWs said that salaries in the industry are not attractive to younger people and that this is one reason why care providers find it so difficult to recruit and retain young staff. This was addressed by a manager who said, *"... we have a huge funding crisis... the staff are paid poorly ... the staff are paid really poorly."* (M2-4) Furthermore, a PSW reiterated this point when she said, *"At the moment, I earn just over \$20 an hour and that's one of the upper amounts you can get and that's only because I have been to Uni... But when anyone who first starts in the job with no qualifications, well that's \$17 an hour ..."* (C1-4)
- Some PSWs felt that their responsibilities were underestimated by management. They suggest many PSWs have left the disability sector because they have not received the recognition of their skills and competencies that they think they deserved: *"... I think the job of support workers are extremely underestimated in this country. I think people don't realise what we do ... You have an extreme amount of responsibility to your clients wherever you go ... and I think that is truly underestimated ... The job, you need a tremendous amount of compassion and empathy and the things you do like cleaning up bodily fluids ... It's very demanding and very much underestimated."* (C1-4)

- Another reason given for high turnover was that there are no clear career paths for PSWs that enable and give recognition to the development of skills and competencies. Some respondents also pointed to the fact that the role of PSW is emotionally and physically demanding which can be harmful to personal wellbeing and constitute a risk to the PSW. These issues are explored further below.

4.2.2. Skills, Training and Workforce Development

Our findings suggest that despite attempts to improve training and development opportunities, in the main, there are few opportunities for developing the skills and competencies necessary for understanding individual client needs and requirements. There is limited access to recognised training programs for vocational qualifications in the sector beyond what is required for induction purposes. This can be seen as a major factor limiting career development and workforce professionalisation:

➤ *Skills and training*

- Equipping PSWs with appropriate knowledge is perceived within service providers as an important issue, especially when agency care workers are replacing permanent PSWs and do not have a full understanding of the client's situation. A client family member from the non-compensable sector told us how they have lost their trust to the care organisations because they had sent agency PSWs who were not qualified and did not have enough information about the person they were meant to be caring for.
- All three service provider organisations provide mandatory induction training for their newly recruited PSWs. This typically lasts two to five days. The induction courses cover introduction to the organisations concerned, Employment Equal Opportunity (EEO) and Occupational Health and Safety (OH&S), professional boundaries, and disability awareness. However, the PSWs said that they found these induction programs to be too generic although they were useful for the initial development of required work related skills. This was also addressed by a manager who said: *"... four days of induction ... is excellent. Unfortunately I find it quite philosophically and aspirationally perfect and they come in, well this happened to me 12 months ago, I was very impressed by the induction with everything I heard, and I came and it doesn't happen."* (M2-4)
- Many managers reported that they were aware of the need to conduct more specialized training. OH&S training was the most frequently mentioned requirement by both managers and PSWs. The sector appears to make little use of the available Certificate and Diploma training for disability work in the Community Services Training Package. This was highlighted by a manager who said: *"... we just do generic training on OH&S. Okay if you're someone in a wheelchair, we need to train, monitor, once in a while come back again. Because some say it might be expensive but I say if there is a complaint and there is serious injury then there is litigation and litigation is going to cost you money ... OH&S is going to cost you money and reputation lots. All this it's up to dollars isn't it?"* (M2-1)
- There are some informal client-specific 'on-the-job' trainings - such as allowing new recruits to work shadow shifts with more experienced PSWs – but little

provision of formal training to enable PSWs to better understand specific clients' need and requirements.

- Several PSWs stress the lack of formal training programs available for PSWs to develop skills and competencies for caring and dealing with ABI/SCI clients. A PSW said: *"There was not particular training for the ABI. Like I talked to my manager here ... and we were like discussing it and maybe soon we will get like specific training for ABI ... like what new developments to understand the behaviour and to handle the situation in some circumstances."* (C2-3)
- However, we observe that one care provider had just started to conduct formal ABI specific training programs, and another one would start later this year. It is too early at this point for managers or PSWs to provide their view on the effectiveness of those training programs.

➤ *Career development*

- Many PSWs identified the lack of career paths as an issue of concern. Some reported that they had been in the disability care industry for about 10 years and still worked as front-line PSWs. As one PSW informed us: *"... it just makes sense to go from the level of hierarchy within the company. But it isn't something that's highlighted and I think it needs to be highlighted because in a way it's sad because I can sort of foresee if people get to the end of their three years of working and they are really, "I can't work physically". They still might want to be involved but they're sort of, "I don't know how to still stay involved with disability", so they might go off and completely change their career path, which is quite sad because those are the people who were quite skilled and have the experience and would be much more valued in the office."* (C1-4)
- A significant proportion of the younger PSWs, who were aged under 30 - many of whom were engaged in study for a higher degree - told us that once they completed their studies they were likely to leave the industry and seek to work in another profession with better job opportunities and career prospects.

4.2.3. Work Roles and Environment

Our findings highlight the following issues in relation to the PSWs' work roles and working environment:

➤ *Isolation*

- Almost all the PSWs engaged in providing attendant care feel that they work in an isolated working environment. Their core tasks involve providing in-house care whilst working alone and as a result there are few opportunities to meet, communicate and share knowledge and experience with colleagues. Contacts often only occur when there is a problem. In such cases the PSWs would report to and seek support from their direct supervisors or case co-ordinators. However, more lateral interactions with other PSWs appeared to be unusual. A PSW said, *"... It would be great to have a social night once a month or have like a yoga class once a month with other support workers, so that you are doing something to de-stress but you feel supported because you are with other support workers ... But it's a very isolating work environment."* (C1-4)

- Some PSWs thought that even an informal mentor for new staff or ‘buddy system’ could be very helpful to address their social isolation with positive implications for service quality.
- Many managers also acknowledge that the isolated nature of the working environment was a problem for PSWs. For example, it is one that may impede information and knowledge sharing with further possible adverse impacts on the quality of services provided for clients. A manager in a focus group said *“The conditions are still really poor, we expect a lot, we work in isolation, it’s hard.”* (FG3-2-A1)

➤ *Work-life balance*

- Most of the PSWs felt that their role was very demanding and some found that it was hard to maintain a work-life balance.
- The majority of PSWs said that there are limited opportunities to report work related problems and the stress generated by their work. Managers, they said, did not generally systematically check on PSWs’ well-being at work. For example, a PSW in a focus group said, *“I don’t know [whether there are any assistance programs available in my organization]. I don’t know of any. Because the government or the individual companies now, they feel they are paying and you do your job, what else.”* (FG1-1-A5)
- Some PSWs pointed out that, whilst service providers emphasised the clients’ needs, they did not normally pay the same attention to the PSWs’ welfare, even though the PSWs typically make personal sacrifices to ensure the client comes first. For instance, a PSW in a focus group said, *“... when they ring you up and they guilt trip you ... or, ‘You know that that client doesn’t have a very big team. I’ve tried everyone, you’re my last resort. Can you please, please do this shift?’ The guilt trip on you when they ring you as well ...”* (FG3-1-A3)
- Some PSWs believed that the situation might be improved if someone in the office at the service provider, such as a coordinators or case managers, had a better understanding of the importance of work-life balance on motivation and performance.

➤ *Safety and emotional wellbeing issues*

- Almost all PSWs mention that OH&S is an important issue in the disability care sector
- Nearly all of the female PSWs pointed out that they were worried about their safety at work, especially those who provided services for ABI clients in an unmonitored environment, such as the clients’ homes.
- The PSWs also pointed out that they needed to be professional and not get emotionally attached to their clients. However, sometimes they said that it was hard to stay immune from such attachments, especially when they had cared for the client for a long time.
- It was reported that some PSWs often decided to leave the disability care sector due to stress related issues arising from the work. This was highlighted by a manager who said: *“... [There are a] lot of stress; a lot of stress claims. So at the moment like our main WorkCover claims are mainly people on*

WorkCover, it relates mainly to stress and depression and the stress has been aggravated of behaviour of clients.” (M1-6)

➤ *Organisational commitment*

- Overall, the commitment of the PSWs to their organisations and the disability industry itself seemed to be low, mainly as a result of issues related to the deployment of skills, career development and the working environment as outlined above. A manager highlighted this problem when she said:
“Unfortunately the management feels that everyone has the same aspirations and philosophies and stuff but it’s not reality.” (M2-4)

Appendix VI provides further views on workforce issues.

4.3. Service Delivery Models

The findings from our interviews with the three service providers, health/allied health professionals and clients reveal three key issues concerning care service delivery models:

- Barriers to a client-centered approach
- Assessing client needs
- Fragmented networks.

These are further described below.

4.3.1. From Provider-Centric to Client-Centered Delivery Models

Our findings suggest that for the service providers, the current service delivery model remains provider-centric and has yet to transition to a fully client-centric approach. This is reflected in the following observations concerning the current model:

- The current models do not appear to be client-focused and there is limited attention by service providers to client preferences and choice. Overall the goal of service delivery appears mainly to address immediate care needs rather than the future long-term goal-setting of clients. In the view of some of our respondents, this had adverse effects on client outcomes.
- Some managers suggested that the current models of care and service do not efficiently utilise the untapped resources of family and friends, (the unpaid carers) for example, in seeking to tailor care plans that are holistic and truly client-centred.
- Despite expressions of enthusiasm there is also confusion about the concept of client-centered care amongst senior level managers in the care-provider organisations and care providers appear to find it difficult to audit the quality and customer experience of service delivery when attendant care is provided in the client’s home.
- Clients and their families in the non-compensable sector (confirmed by health and other practitioners) felt they were neither empowered with the relevant knowledge nor the skill to navigate through the complex environment of systems and processes involved in sourcing services. It was said in the non-compensable

sector that navigating through the multiple layers of service offers successfully frequently required a highly skilled and knowledgeable individual (or 'champion') to act for the client and to be able to broker services to meet the client's needs.

- Clients in the non-compensable sector (or their champion's) felt that their voices were often 'drowned out' and that they did not have much say in the choice of treatment/rehabilitation and, by the same token, were not always informed, consulted or included the decision-making. Similar views, albeit for different reasons, were put by clients and their families in the compensable sector. For example, one client claimed a little ironically: "...well this is part of a process of independent living. I mean TAC didn't want us sitting around in a rehab hospital forever ... I mean they're thinking, 'Well, you know, how much longer'... Well I was happier at [name of rehab hospital] because they gave you all your meals and stuff." (CL1-2)

4.3.2. Assessment of Needs

Overall, our findings suggest that there is an absence of procedures, processes and practices that enable a 'joined-up' or holistic assessment of needs against agreed care standards by all agencies and disciplines involved in providing long-term care. In the views that were articulated to us at least, this was the case for clients both in the compensable and the non-compensable sectors:

- The absence of a holistic approach was said to be mostly significant at the critical early intervention acute phase in the care pathway where the interfaces between medical, allied health and social care disciplines were the keys in determining an overall care plan and pathway for clients. This point was emphasised by a medical practitioner in a focus group when she said: "*the value-add from each group is different and the care language...we speak different languages too between the disability services and the medical team*" (FG-A1). A further comment suggested that TAC had potential conflicting roles in this process that meant it did not necessarily provide a means of providing a more joined-up process: "...TAC is in a conflicted position as an insurer, broker and tries to be treater and influence practice." (FG-A1)
- The general consensus among the professionals and practitioners we interviewed was that a multidisciplinary approach involving medical, allied health and social care expertise was the key to optimise client outcomes in a longer term in the context where advances in medical treatment are significantly improving the chances of survival from traumatic injury. Such a view has been argued by research on ABI which suggests that a holistic approach involves drawing appropriately from multiple disciplines to redefine problems outside of normal boundaries with the aim of reaching solutions based on a new understanding of complex situations.²² However, amongst our interviewees there was a strong perception that the current models of care lacked such a capacity to the work outside of 'normal boundaries' and that there was an absence of recognised standards which might support such a holistic assessment. Such an approach, as evidence elsewhere might, for example, provide a good indicator at

²² National Board of Health. (2011). *Brain Injury - A Health Technology Assessment*. Denmark: National Board of Health, Danish Centre of Health Technology Assessment (DACEHTA).

the early intervention stages of longer term care needs and requirements²³. In the absence of such an assessment, as suggested by our respondents, the problem of care-giving was exacerbated and this negatively impaired client recovery downstream.

Our findings highlight various perceived constraints concerning improving the assessment of client needs and early intervention, particularly at the acute phase:

- Highly specialised professional practitioners report that, whilst a multi-disciplinary approach may be needed, it is not always easy to work well with the practitioners of other disciplines. For example, a health professional complained about the difficulty of providing integrated services: *“A young man with ABI from a small country town who after being released from hospital-care returned back into the medical system with complications due to “a litany of terrible planning” in his medical care due to variety of neglect from other disability and community services...”* (FG-A1)
- There was acknowledgement amongst interviewees that there are currently system-wide gaps and overlaps between primary care medical/clinical areas and secondary allied health services and other community and disability care agencies. For example, a manager in a focus group disclosed that: *“Although [CP1] is a disability service, we are in the health industry because all our clients have a health issue.”* (FG1-2)
- Where a more holistic approach on the part of service providers did take place, this, it was said, often happens ‘too late’ as it takes place after the acute phase and thus the potential benefits of more early interventions by a range of health and social care disciplines are missed.
- There was a perception amongst service providers that service commissioning/funding agencies such as TAC influence the care plans of client’s with specialised care needs with inflexible generic models which may conflict with the expertise and advice of the medical or allied health groups. Such conflicting perceptions are indicated in the following comment from one of our focus group: *“...anyway, the case managers will go in and do their assessments but they do it in conjunction with the allied health workers. And sometimes it’s interesting that I’ve actually been told that in fact there can be quite a difference in what the allied health team perhaps think that somebody needs as opposed to what is actually required on the ground”*. It was highlighted to us that *“sometimes the allied health staff think that people need a lot more and they need certainly the Rolls Royce, if you like, kind of equipment....”* (FG-A3)
- There were anxieties expressed by some professionals that despite the enthusiasm of the development of independence plans for TBI clients, it also needs to be tempered by an acknowledgement that some clients with severe impairments will naturally and progressively get worse due to age related complications and the like.

²³ For example, the Glasgow Coma Scale (GCS) and its expanded Glasgow Outcome Scale (GOS) and Extended Glasgow Outcome Scale (GOSE) are used in both American and European neurological centres to predict the future prognosis of a TBI patient. What happens at the acute phase is seen as a critical point in determining the life-long prognosis of an ABI/SCI person.

4.3.3. Fragmented Networks of Care Delivery

Our conversations with medical and allied health professionals as well as care provider organisations indicate the absence of a strong model of partnership and collaborative work between agencies and service providers engaged in health and social care. However, TAC plays a key role in assessing clients' needs and offering options from which they can make their choices in selecting suitable service providers. However, overall our findings suggest that the current care and service delivery environment is not based on a strong model of partnership and multi-agency working:

- Much of the 'joining-up' that occurs in the current system is clearly reliant on independent passionate professionals who often have to go beyond their call of duty to help vulnerable clients in a sector that is stretched for resources of all kinds.
- The current models of care lack coordination between multiple service providers. This is highlighted by clients and their families as well as practitioners from specialized discipline areas. As noted above, specialists acknowledge that they 'speak different languages' based on the traditions within their own-specialised areas of training and that this makes communicating with practitioners from other disciplines difficult, let alone for the client in dealing with a range of practitioners from different disciplines.
- Although on the surface it appeared that TAC had a better coordinated system in place compared to the non-compensable sector, its effectiveness was questioned by some of our respondents. One manager commented in the following way: "... TAC actually talks about that [coordination]...., that when somebody's in the acute that they get this coordinator and...upfront. And so I assume, 'Well that's great because that's happening at least for those clients' but perhaps it's not happening as well as it should... Yeah. Because the language they speak, first of all, is different languages, the medical side to the OT [Occupational Therapist] side to everything else, you know. So it's not like... They do speak very differently at times." (FG-A3)
- We observed that there are some early and new efforts to address the issue of partnership working at the sub-regional level as a means to promote high quality and citizen-centric services as part of a deliberate 'place-making' strategy for the 'city-region'. These activities and strategy provided a plausible example of an attempt to coordinate various government and community organisations in a geographically large and dispersed region across several municipalities with a particular emphasis on providing services to vulnerable groups such as those with disabilities.
- Fragmentation is exacerbated by and itself exacerbates the problem of relatively small numbers of clients being dispersed over large geographical areas - and in some instances remote and rural locations - posing resourcing challenges to care providers. This also puts a particular stress on PSWs serving clients and is likely to disadvantage clients living outside of the main urban areas. This was highlighted in a focus group when it was pointed out: "*The more remote they are the tougher it can be.... And we do have some clients' interstate as well.*" (FG-A2)

- The fragmented network of services is cumbersome and resource intensive and almost certainly results in waste and duplication of efforts which are likely to increase costs of delivering care and undermines in the efficiency. For example, we were told by some PSWs and clients that it was not uncommon for errors in rostering of PSWs which resulted in two persons turning up in one location when only one was needed, or, sometimes no one turning up at all. This poses not only issues of inefficiencies but potentially results in increased risks to vulnerable clients who may find themselves with no aid at a time when it is needed. Another example was provided by a PSW who related the problems arising from irregular care reviews: *“One of my clients has cognitive abilities, that guy with the epilepsy, his cognitive ability has deteriorated terribly but he’s in the old people’s home and they just get left there. And I find it increasingly more difficult to have a conversation with him and there have been no updates or anything. I did contact my coordinator and I said I was concerned about the amount he was eating and the amount he was going out and having the big meals and he’s got diabetes. And I said, ‘If I didn’t mention anything I wouldn’t feel comfortable if something happened.’”* (C1-6)
- Although there are some innovations and efforts (such as the implementation of the “independence plan” by TAC) which aim to establish a more coordinated approach, to date none of these initiatives appear as yet to have been comprehensive and broad enough to tackle the poor coordination of the entire service delivery for ABI clients at a system level.

Appendix VI provides further views on service delivery models.

4.4. Service Innovation and Technology Implementation

The findings from our interviews in the three service providers of service managers and PSWs and clients/family members revealed the following issues concerning service innovation and technology implementation:

- Variable and fragmented information for clients
- Lack of information sharing
- User requirements

These are further described below.

4.4.1 Information for Clients

There is inconsistent and fragmented information available to clients about service offers and the procedures and processes involved to access and use them (including systematic information on other users’ experience and perception of value).

- Paper-based media are typically used to communicate service offers e.g. as found in display racks at the many care provider, health and voluntary and community organisations engaged in the sector, see Figure 4.1. Elsewhere it has been shown that, in the case of information provision for patients and their carers after stroke, information provision in the form of leaflets, booklets and manuals is not effective and has no effect on quality of life for clients and their informal

caregivers, perceived health status and improvement of the clients' mood.²⁴ This suggests that the current form of giving information to clients through brochures and booklets does not provide them with a holistic view of the available services and the required processes to get access to what they need.



Figure 4.1: Paper-based Communication of Service Offers

- Clients and their families from both compensable and non-compensable sectors informed us of their feelings of confusion in organising accurate and relevant care plans for their needs. This was partly due to the way information is transmitted to clients and their families. In this respect TAC clients appear more fortunate in the sense that they have a case manager who acts as an intermediary to assist in dealing with access to information.
- Clients and families reported that they often discover information that was crucial to them and it was often by chance. For example, simply meeting at random a knowledgeable or kind person who 'knows the system'. As this non-compensable client's family member informed us: "...over four years. Our family...actually we, again, I mean the family did a great job and our team, we

²⁴ Forster, A., Smith, J., Young, J., Knapp, P., House, A., & Wright, J. (2001). Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews*.

just located a team of physio team, physio, occupational therapists and a speech therapist.” (CF2-1)

- PSWs do not have access to a comprehensive service directory so they are not able to assist clients in any systematic way. For example a family member from the non-compensable sector said: *“The OT even complained that she couldn’t just get on the computer and it wasn’t all just there for her so she couldn’t follow a certain branch, if you need this help you can go this way, if you need these supports you can go that way.” (CF3-1)*

4.4.2. Poor Coordination and Information Sharing

There is a poor coordination and information sharing across different service providers in the sector. There are limited internal information and feedback flows within care organisations in relation to both client experience and workforce deployment and performance. These information coordination problems bring a number of consequences as follows:

- Clients have to repeat their stories, needs and goals to every service provider (involving many people and points of contacts) over-time since important information about each client is distributed across the service delivery system within different service ‘silos’. Therefore, they have little sense of shared plan guiding their long-term care. For example, it appears that at the acute phase the person who typically makes the initial assessment with the client is different from the person who develops the care plan. Similarly, the person who manages the rostering and planning of attendant care post the acute phase and the person who updates and revises the care plan and the person who follows up any incidents or acts on client or PSW feedback are also all different.
- Although the assessment reports sent to care providers by TAC is often predetermined and clear there is no clear consistency in the reporting structure to capture all the relevant information relating to the unique needs of different individual clients. What is recorded seems to be totally dependent on the person who writes the report and what they think is appropriate to record and in what level of detail. Managers reported that referrals sent to care organisations quite often do not match the client’s needs. As a manager mentioned: *“I would say that I’m happy with the level of information that comes through. I don’t think it’s perfect all the time. I think there are opportunities for improvement there but we’ve very much spoken to our consultants and our staff to seek out further information if that’s required.” (M1-1)*
- Unsurprisingly, we found little evidence of any systematic means of gathering and analysing aggregate data with a view of finding patterns in terms of client experience with service delivery or outcomes which might then inform subsequent resourcing or strategic decisions over what and how to provide or target specific services. Similarly, the reporting and recording of incidents at an aggregate level and sharing this information with all the relevant parties and agencies to review individual incidents did not seem to take place systematically. As one manager observed: *“...if you can get more information from the start, in the future you will have fewer problems... informational gaps exist when people are discharged from hospital with regard to assessment of needs and this first assessment is critical.” (FG1-2)*

- There are indications that not having access to the right information at the right time causes redundancies and inefficiencies in sharing information across different agencies as a result of fragmented information systems within and between service providers. For example, a manager in a focus group mentioned that: *"This disconnect needs to be addressed as we want the ability to go upstream if we need to, such as with TAC or occupational therapists, to identify areas for interventions. We want to connect more with clients."* (FG1-2)

4.4.3. Limited Internal Information and Feedback Flows in Care Provider Organisations

The importance of access to timely and accurate information about clients' needs and communicating this information across the organisation from the 'front-office' of attendant care through to the 'back-office' of coordinators and planners was recognized and was a matter actively being addressed by managers within the resource and other constraints that they faced. However, it was clear that there are several challenges and issues to be overcome:

- We were advised by PSWs and clients that care plans are not updated regularly and that PSWs do not find them useful and informative. Similarly, the valuable knowledge of PSWs who work with one client for a long period of time is not routinely captured and documented in any systematic way which might permit it to be readily made available to be transferred to other carers or used for updating care plans. As one PSW reported: *"they throw you in the deep end sometimes and that's where the challenging part comes into it. You know no history of the person, what they dislike or they like and if they can't talk then I just don't know what to do."* (C1-1)
- We observed that the three care provider organisations had developed and deployed information systems to help them manage and process information more effectively and efficiently. However, these seemed as yet not to be informing operational and strategic decisions which were proactive in controlling risks and errors. For example a manager informed us: *"It [information flow within the organisation] is not the best and the only reason why I say that is because at times there are informal processes, there's not really formal processes in place.... So not in all situations are we being preventative at the moment and that's what we're looking to move towards."* (M1-5)
- PSW respondents suggested that not having access to accurate, timely and appropriate formatted information about clients was one of the biggest problems that they faced. For example, a PSW mentioned that: *"I suppose [CP1] should actually inform each carer with a care plan for each person that we deal with, because a lot of the cases I don't know what I'm dealing with. So you roll up to a job and there's a person laying in bed and you don't know if he's got muscular dystrophy, spina bifida, I just don't know what you're dealing with. So a lot of the cases it's like that and I think you need some sort of paperwork or assessments or a case history of people. So like we did in nursing.... So that helps you, it helps the carer be involved and be aware of what you're dealing with."* (C1-1)
- We learnt from several carers about the challenges they faced when their support organisations do not provide them with comprehensive history of the patient. As a manager emphasised: *"...if they [carers] don't understand why that client is acting in that way or they feel that they're not equipped with the*

knowledge or the skills of the different strategies in order to de-escalate situations, then it seems something then that's out of control and then it just leads to more stress on their part." (C1-1)

- Our findings indicate that within care providers different parts of the organisation do not 'talk to each other' in a systematic way to share information about clients where appropriate. As a result, there is no clear and regularly updated 'view' of the client, but rather partial 'views' held by different organizational members. For example, we found that there are no procedures apparently in place which require PSWs record important episodes, events or issues, or to feedback their assessment of the client's needs etc. We were told about some incidents experienced by clients that apparently had resulted from miscommunication within the care providing organisation which resulted in negative effects on the client's health and well-being. One PSW told us about his experience: *"I think things can be a little bit better with communication. Regarding [name of client], like he had a bit of a rash some time ago and obviously one worker had noted it down but we had another staff member who didn't write what was discussed between the locum doctor. My concern was that any information that is not noted down between the locum doctor and the staff member we don't know what's going on, how serious is the rash."* (C1-8)
- We have already noted above some of the issues involved in managing a mobile workforce of attendant care workers and that errors in rostering are not uncommon. For example, a client from the compensable section informed us: *"Yeah. There's areas for improvement.... I don't know, they keep making simple mistakes like for me two or three people turned up to do a shift and they don't communicate well with their staff. Three turn up when it's meant to be ... one"*. (CL1-3). We observed in one organization that even gathering basic information for time-sheet purposes had only just transitioned from an entirely paper-based system to one with a degree of computerization and a 'semi-automated' means of gathering information from PSWs (involving accessing an automated recording system using – if the client consented - the client's telephone). A manager emphasised the need for improving the management of mobile workforce when he said: *"Our workforce is so, so remote..., we need to have a way to capture that easily, using technology.... Definitely an area for development."* (M1-2)
- In the institutional homes we visited, the quality of information and the process of sharing information did appear to provide a more holistic view of the clients. For example, we observed a variety of means through which information was recorded on a day by day basis to ensure informed, consistent and appropriate care through such means as notice boards or communication books used to record important issues that could then be shared amongst the carers on different shifts and so forth. However, there appeared to be no format for documenting the information or a process for sharing and controlling the reports over-time to build up, for example, a historical record that might inform future care planning.

4.4.4. Little Systematic Engagement with 'Users'

Our interviews and focus groups confirmed that there is great interest amongst clients and the care sector in finding ways to benefit from the potential of using new information and assistive technologies in long-term care. In instances where

assistive technologies had been adopted, there appeared to have been little systematic engagement with 'users', i.e. clients and their networks and service delivery agencies, to identify needs and requirements to specify informational and assistive requirements. Getting a better match between actual needs of both clients/families and care providers (the 'users') on the one hand, and the design of systems and devices that were procured and deployed, on the other hand, is likely to be an issue with greater deployment of assistive-technologies in long-term care.

- Clients and their families expect and are looking forward to the benefit of using new technologies and having access to information about available services, especially when they have more control, choice and responsibility over their care plan. We have been told about the lack of improvement and innovation in the sector. However, given the changing policy context, clients and their families now seem to have higher expectations that assistive and other technologies will be made available to help them in the future.
- There was also obvious interest on the part of clients and their families to have further access to information and assistive technologies in their homes to improve opportunities to have an independent and safe living environment. For example, one client from the non-compensable sector told us about the risk of burning himself when cooking and his desire to have a better designed kitchen that would reduce such risks. He mentioned: *"No. I don't think it's a perfect design. Maybe an island bench or something would be good or a trolley, so you don't have that risk of burning the tops of your legs. You just have to be very careful with what temperature you use."* (CL3-2)
- In spite of the recognised needs and high expectations amongst care providers and clients, we were told that the availability and take-up of new technologies in the sector is generally seen to be very low (in one of the institutional homes we visited we noted the expense of seemingly basic technologies such as shower chairs). The main reasons for this are a lack of available financial resources, of course common in the not-for-profit sector, and a lack of investment in appropriate research to evaluate, with clients and carers, what might work and have beneficial impacts for both clients and the sector. As a manager declared: *"It is a very expensive move, the transition to new technology. So it's always in the too hard basket. But it is so important."* (M2-4)
- There was a view expressed by some service providers that many clients and PSWs lacked 'computer literacy' and/or were concerned about the capacity of service provider organisations to support a more the use of new technologies. One manager informed us, *"...for me, you need to have that infrastructure somewhere to support that so issues and complaints, how to handle it, you don't have that level of support. Because any technology needs that kind of backup support if something goes wrong. Like universities are great, they have AVA technicians and all that, we kind of don't."* (M2-1) However, the lack of the required infrastructure and organisational capability and resources to pursue such innovation suggested that such concerns were not necessarily based on much, if any, actual experience.

Appendix VI provides further views on innovation and technology implementation.

The next section presents discussion based on our findings reported above.

5. Discussion

In this section, we structure our findings in the context of our four research objectives and place them in the broader context of relevant research findings and experience elsewhere. In the following concluding section, by way of recommendations, we outline a number of proposed interventions intended to improve and innovate the way in which human resources, service delivery and information might be better organized and managed in the service delivery process. The potential improvements and innovations that we identify would involve co-design and co-production with services providers, clients and their networks and other stakeholders. In exploring the implications of our findings, it should be borne in mind that they represent preliminary outcomes from a pilot study intended to scope possibilities and options, not provide definitive solutions, for service delivery improvement and innovation.

5.1. Implications of Changing Context and Client-Centred Care

Our findings indicate that new client-centered approaches being promoted at the whole sector level (NDIS) or in the compensable sector (e.g. TAC) require more co-ordinated services and delivery and that this presents a number of challenges and issues for both service providers and the existing service model in terms of human resourcing/development, business process improvement and technology-supported innovations in service delivery:

- *Challenges for support workforce resourcing and development:*
 - Mismatches between client care needs and capabilities and experience of care workers
 - Skills training and development deficiencies
 - Working environment challenges
- *Challenges for business process improvement in service providers*
 - Poor quality of information in terms of accuracy and coverage
 - Barriers to information sharing in a safe, timely and governable manner
 - Fragmented and duplicated information available to clients and service providers only through cumbersome and hard to understand processes
 - Limited internal information and feedback flows within service provider organisations in relation to both client experience and workforce performance.
- *Challenges for technology-supported service innovation by providers and at a whole system level*
 - The delivery of client-centred care policies and strategy intended to provide more integrated care is constrained by provider-centric approaches to service delivery (evidenced, for example, by an apparent lack of future focus on the goals of independent living in day-to-day practice).
 - Current service delivery models are fragmented and poorly co-ordinated (evidenced, for example, by the absence of an effective means to provide a holistic assessment of client needs and aspirations across care providers) and the system requires significant 'bottom up' integration by clients/families and their supporters.

Our findings suggest that, despite the prevailing rhetoric of the need for a more client-centred focus, the reality is that care sector service providers are experiencing many challenges and obstacles in adopting new care models. As a result, they struggle in providing a more joined-up experience for clients in the way that services are provided and co-ordinated with other service providers. It is clear that the service providers we talked with – and we have no reason not to believe that they were typical of the sector– were at the start of the journey towards a more coordinated approach which might deliver the kind of seamless delivery of services that many see as essential to improving client experience and outcomes.

This is not to say that the experience reported by clients and their families was one of total fragmentation and lack of co-ordination. Indeed, this was highlighted in particular by clients we interviewed from the non-compensable sector. This suggests that they, in some instances at least, manage to effectively use their own resources to assemble a host of services and therapies unique to the customised needs of the client. In such cases it was apparent that clients and their families sometimes working with service providers and other agencies or individual advocates within them, seemed to have been able to broker together and provide the necessary intermediation required to ‘join things up’ to better suit their needs and requirements. In these instances, they seemed to have developed their own ‘client service delivery networks’, perhaps despite rather than because of, the more fragmented service delivery model around them.

This information from the non-compensable sector - confirmed by several service providers and practitioners - highlights that despite being less-supported, these clients seemingly have greater incentive to broker required services based on their real needs where they are represented by strong caring advocates. When faced with significant challenges, such advocates for vulnerable clients become resourceful and committed towards achieving the best care possible for their loved ones. We explore below some of the implications of this for improvement and innovation in service delivery in the compensable sector.

5.2. Future Training and Development Requirements and Workforce Profile

Our findings suggest that there is a major need to improve the capability and quality of the workforce and the managerial capacity and resources available to manage the delivery of care in a more cost- effective, high quality and client-centred way. This is unsurprising and consistent with other studies which have looked more generally at the care workforce.

For example, a comprehensive report by the Australian Health Workforce Institute points out that carers (paid and unpaid) are an under-utilized resource²⁵. They are not often acknowledged for their role by health professionals and are not engaged as partners in care. The report presents several recommendations for recognising the role of care engagement in assessment, care planning, service delivery, discharge planning and other patient care activities. These recommendations were aligned to and supported by several policy documents, such as the Australian Governments

²⁵ Brooks, P. (2012). The role of carers and volunteers in the Australian health workforce: caring in partnership. Health Workforce Australia.

Charter of Rights and Responsibility for Community Care, the National Carers Strategy and Priority 1 Recognition and Respect. The report also addresses financial and emotional support required by carers to ensure their continued effectiveness.

The development of a healthy and productive workforce requires effective policy intervention. At the national and industry level, this may take the form of industry-based regulatory intervention. At the organisational level, this includes a well-developed training and development system. Despite the fact that non-clinical care workers make up at least 65 per cent of the care workforce, and whose skills are also in increasing short supply, limited actions have been taken at the policy and organisational level to address this exacerbating problem. This inadequacy may have in large part to do with a broader societal undervaluing of caring work and an incapacity of economic markets to truly reflect the worth of care.²⁶

The delivery of good care services requires a well-skilled and highly committed workforce sustained by good HRM policies and stable employment relationships.²⁷ However, existing evidence suggests that the care industry suffers from poor terms and conditions, high work intensity, recruitment and retention difficulties, inadequate training and development provision, and poor leadership/management problems, with residential aged care seemingly suffering more than other categories of the social care.²⁸

Poor terms and conditions and relying on the good-will and willingness of the care workers to provide care services have been found to be a common practice in other developed nations such as the UK.²⁹ Care workers derived their job satisfaction from knowing that they are doing a worthwhile job but are often unhappy with their low pay and workload intensity.³⁰ Therefore, this good-will cannot be taken for granted nor can it be sustained in the long-term.

At the organisational level, the HRM problems identified in our study will not only impact on the quality of care service, but also carry strong gender, race and cultural implications, given the fact that a significant proportion of the carers are women and workers from ethnic background (e.g. international student workers). At the societal level, these problems may add further tension to issues related to disability care, social inclusion and systemic disadvantage. Over a longer period, we may also see the deterioration of job quality on the one hand, and the decline of service quality of disability care on the other.

²⁶ Nelson, J. (1999), 'Of markets and martyrs: Is it OK to pay well for care?' *Feminist Economics*, 5(3), pp.43-59. Kaine, S. (2012), 'Employee voice and regulation in the residential aged care sector', *Human Resource Management Journal*, 22, 3, pp.316-331.

²⁷ Jeon, Y. H., Merlyn, T. and Chenoweth, L. (2010), 'Leadership and management in the aged care sector: A narrative synthesis', *Australasian Journal on Ageing*, 29(2), pp.54-60. Rubery, J. and Urwin, P. (2011), 'Bringing the employer back in: Why social care needs a standard employment relationship', *Human Resource Management Journal*, 21(2), pp.122-137.

²⁸ Aged and Community Services Australia (2007), 'Working together: Aged and community care workforce', Background Paper, September, Internet source: <http://www.agedcare.org.au/what-we-do/workforce/workforce-pdfs/Working-Together-Background-paper.pdf>, accessed on 14 October 2011.

²⁹ Rubery, J. and Urwin, P. (2011), 'Bringing the employer back in: Why social care needs a standard employment relationship', *Human Resource Management Journal*, 21(2), pp.122-137.

³⁰ Martin, B. and King, D. (2008), *Who Cares for Older Australians? A Picture of the Residential and Community based Aged Care Workforce*, National Institute of Labour Studies, Flinders University, Australia.

Standards setting bodies have argued that the providers of care services should have in place systems to ensure that the right people are recruited and that employees have the relevant qualifications, knowledge and skills to effectively deliver quality services to people with a disability. Similarly, available research strongly supports the view that a skilled and well-supported workforce can ensure that care is reliable and responsive to clients' needs, can foster social participation, and assist clients and their families to take more control in defining and meeting their support needs.^{31,32,33} Such a workforce can also sustain good care relationships between paid support workers and the service users (clients), which can reinforce clients' self-esteem and dignity.

Access to a well-supported, sustainable workforce can also improve trust between care workers and service users and relieve stress among these carers, to improve their quality of life and service provided for clients. By the same token, good quality services are also linked to good working conditions and it is important to manage the risks associated with care working such as isolation, work-life imbalance and risks to health, safety and well-being at work. Several studies and reports have pointed to the fact that care providers in Australia find it difficult to attract and retain skilled disability care workers, affecting the quality and variety of services available.^{34,35,36} This is linked to the fact that, in practice, there is very limited organisational support for carer learning and development in the Australian disability care sector beyond mandatory courses and induction. The quality of training provided in the sector is also recognized as generally less than satisfactory.³⁷

5.3. Business Process Improvement and New Service Models

Our findings suggest that achieving the objectives of a more client-centered approach will ultimately require new service models to be developed at a whole system level and adopted by the multiple agencies in the frontline of delivering care services to clients. The overarching issues in many instances, at least where complex needs are involved requiring the support of a wide range of professional expertise and different providers over time, is the problem of reconciling the very different 'views' of 'the patient/client' which are embedded in existing 'provider-

³¹ Disability Service Standards Working Party. (2002). National Standards for Disability Services, from http://www.health.nt.gov.au/library/scripts/objectifyMedia.aspx?file=pdf/14/83.pdf&siteID=1&str_title=National%20Disability%20Standards.pdf.

³² Blyth, C., & Gardner, A. (2007). We're not asking for anything special: direct payments and the carers of disabled children. *Disability & Society*, 22(3), 235-249.

³³ Cortis, N., Meagher, G., Chan, S., Davidson, B., & Fattore, T. (2013). *Building an Industry of Choice: Service Quality, Workforce Capacity and Consumer-Centred Funding in Disability Care*. Sydney: Social Policy Research Centre, the University of New South Wales.

³⁴ Vernon, A., & Qureshi, H. (2000). Community care and independence: self-sufficiency or empowerment? *Critical Social Policy*, 20(2), 255-276.

³⁵ Cortis, N., Meagher, G., Chan, S., Davidson, B., & Fattore, T. (2013). *Building an Industry of Choice: Service Quality, Workforce Capacity and Consumer-Centred Funding in Disability Care*. Sydney: Social Policy Research Centre, the University of New South Wales.

³⁶ Martin, B., & Healy, J. (2010). Who works in community services? Adelaide: National Institute of Labour Studies.

³⁷ Fattore, T., Evesson, J., Moensted, M., & Jakubauskas, M. (2010). *An examination of workforce capacity issues in the disability services workforce: increasing workforce capacity*. Unpublished final report: Community Services and Health Industry Skills Council.

centric' organisational 'silos' and associated fragmented service delivery models.^{38,39} However, there is scope for immediate improvement by addressing the efficiency and effectiveness of the existing business processes within service providing organisations. Service provider benefits have also been shown to have arisen from the adoption of lean and continuous improvement methods, albeit more in the health care rather than social service domain. For example, Flinders Medical Centre in South Australia has been one pioneer and had conducted a series of care redesign programs since 2003. These have produced benefits such as reducing cost and improving service safety and quality (see Box 5.1).⁴⁰

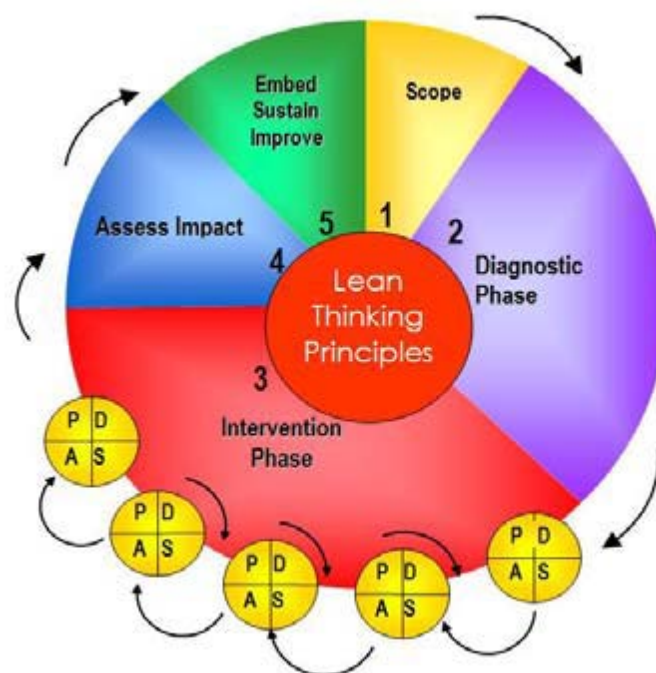
³⁸ Disability Service Standards Working Party. (2002). National Standards for Disability Services, from http://www.health.nt.gov.au/library/scripts/objectifyMedia.aspx?file=pdf/14/83.pdf&siteID=1&str_title=National%20Disability%20Standards.pdf.

³⁹ Kodner D (2009). All together now: a conceptual exploration of integrated care. *Healthcare Quarterly*, 13(Sep), 6–15.

⁴⁰ Ben-Tovim, D.I., Bassham, J.E., Bolch, D., Martin, M., Dougherty, M., & Szwarcboard, M. (2007). Lean thinking across a hospital: redesigning care at the Flinders Medical Centre. *Australian Health Review*, 31(1), 10-15.

BOX 5.1: Process Improvements from the Application of Lean Thinking In Health Care Service Delivery

Over the past ten years, Flinders Medical Centre in South Australia has conducted a series of care redesign programs to tackle bottlenecks in the patient journey and improve the patient experience. Benefits such as reducing cost, improving service safety and quality, improving employee satisfaction and making care more accessible have been achieved.⁴¹ This has been achieved through the implementation of a series of lean programs (called Redesigning Care), first tested in the Emergency Department and then rolled out across the hospital. The overarching goal was the provision of the right care for the right patient, at the right place, at the right time and through the right process. The Redesigning Care programs consisted of 5 steps (scoping phase, diagnostic phase, intervention phase, assess impact and evaluation, and continuous improvement). The scoping phase included identifying flow and process that needs improving and identifying the key stakeholders involved.



The diagnostic phase aims to achieve a deep and shared understanding of the current service delivery state through mapping the service flow and tracking the patient journey. Key performance indicators (KPIs) are also identified in this phase. The intervention phase involves a learning process achieved through a series of 'Plan, Do, Study and Act' (PDSA) cycles. These interventions are undertaken in line with the KPIs by people in different work groups. When these interventions are introduced, evaluation on the effectiveness of current interventions is also carried out to identify possible future interventions. Overall, the lean model is a continuous improvement process, which requires the organisations to keep measuring and rechecking redesign needs, identifying and implementing new possible interventions and improving patient outcomes.⁴²

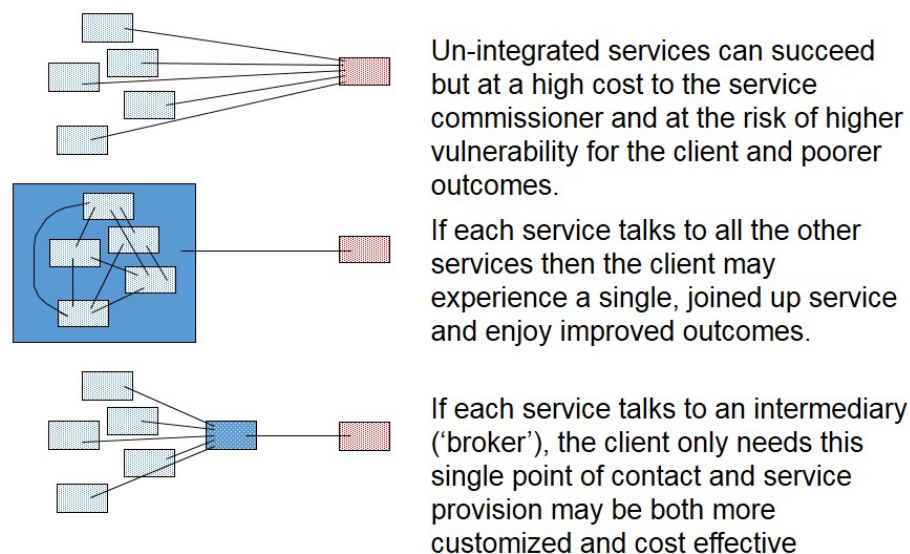
⁴¹ Ben-Tovim, D. I., Bassham, J. E., Bolch, D., Martin, M. A., Dougherty, M., & Szwarcbord, M. (2007). Lean thinking across a hospital: redesigning care at the Flinders Medical Centre. *Australian Health Review*, 31(1), 10-15.

⁴² SA Health. Retrieved 20 July, 2013, from http://www.flinders.sa.gov.au/redesigningcare/files/pages/redesigning%20care/learning_by_doing_fs_20100.pdf

A report assessing the care system for patients with ABI in Denmark showed that while the easy and on-time access to the patient assessments and reviews of patients' needs are vital to provide the right services at the right time, inadequate flexibility and coordination inside and among the service providers makes it difficult to get access to the patients' latest updated assessment⁴³. Weak links within the service supply chain cause delays and increase the costs of the overall treatment processes. A study on TBI patients in the US⁴⁴ identified that the weakest link is at the stage of transferring patient with TBI from tertiary care program to rehabilitation organisations which provide long-term care.

As our findings suggest, the overarching issue of the disability care sector seems to lie in the degree to which services are not joined-up and focused sufficiently on the individual needs, aspirations and goals of clients. This situation is illustrated in example a) in Figure 5.1. Such un-integrated services can succeed but at high costs to those commissioning and resourcing them. Indeed, as we have indicated, one element of such success is what can be termed the 'bottom up' integration engaged in by clients, families and others some of who work assiduously to and have become very adept at 'joining-up' the system for themselves.

The Benefits of an integrated service model



Adapted from Martin 2000

Figure 5.1: Benefits of an integrated service model
(a) Un-integrated service model; b) Joined-up service model; c) Brokerage service model)

⁴³ National Board of Health. (2011). *Brain Injury - A Health Technology Assessment*. Denmark: National Board of Health, Danish Centre of Health Technology Assessment (DACEHTA).

⁴⁴ Khan, S., Khan, A., & Feyz, M. (2002). Decreased length of stay, cost savings and descriptive findings of enhanced patient care resulting from an integrated traumatic brain injury programme. *Brain Injury*, 16(6), 537-554.

The proposed alternative to this model normally takes the form indicated in example b), Figure 5.1. Here, service re-design is proposed which seeks to develop a fully integrated system where information – typically in digital form - is shared ‘vertically’ between service commissioners, service providers and service clients on the one hand and ‘horizontally’ between commissioning agencies, providers and between clients (e.g. through facilitated networks). In practice such integration has and continues to prove extremely difficult to achieve, especially when attempts are made to scale beyond the local context, not least because of institutional and cultural barriers to such change.

However, there is evidence from disability care services that such integration, when achieved, delivers significant benefits. For example, in a study of integrating the process of care from pre-hospital phase until discharge to long-term care facilities for patients with ABI in the USA, the records of 1,875 patients with mild, moderate and severe brain injury were reviewed. The results showed the reduction of average length of stay from 30.5 days to 12 days which resulted in significant saving of \$21.8 million during 6 years.⁴⁵ Other research also suggests that integrated models of care are not only feasible but also enhance the efficiency and sustainability of the care system. Integration also claimed to deliver other benefits, such as improved quality of services and clients outcomes, especially for clients with complicated, clinically challenging and very costly conditions^{46,47}. For example, in Quebec after four years of implementing integrated service delivery for frail older people the annual incidence of functional decline was half of the incidence in the comparison group. Lower number of visits to emergency rooms and hospitalisation, higher satisfaction and empowerment are some of the other results of the coordinated system of care.⁴⁸ Similarly, the “one-stop” service delivery model have been shown to improve client experience, and, to certain degree, client outcomes.⁴⁹

A third model – example c) in Figure 5.1 - seeks to achieve some of these benefits but without seeking to fully integrate services as a pre-requisite. The aim here is to provide the client with one point of contact to an intermediary or brokering agent(s) which seeks to co-ordinate services in a manner that better meets individual client needs and can be more cost effective.

Whilst experiencing elements of the lack of co-ordination in service delivery, it would seem that client’s in the compensable sector served by TAC enjoy a higher degree of integration in terms of the identification of needs and the packaging of services to meet those needs within the provisions and entitlements defined by the scheme. In other words TAC itself fulfills some aspect of the brokerage role. This role might

⁴⁵ Khan, S., Khan, A., & Feyz, M. (2002). Decreased length of stay, cost savings and descriptive findings of enhanced patient care resulting from an integrated traumatic brain injury programme. *Brain Injury*, 16(6), 537-554.

⁴⁶ Kodner, D. L., & Kyriacou, C. K. (2000). Fully integrated care for frail elderly: Two American models. *International Journal of Integrated Care*, 1(October – December).

⁴⁷ National Board of Health. (2011). *Brain Injury - A Health Technology Assessment*. Denmark: National Board of Health, Danish Centre of Health Technology Assessment (DACEHTA).

⁴⁸ Hébert, R., Raïche, M., Dubois, M.-F., N'Deye, R. G., Dubuc, N., & Tousignant, M. (2010). Impact of PRISMA, a coordination-type integrated service delivery system for frail older people in Quebec (Canada): A quasi- experimental study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65(1), 107-118.

⁴⁹ National Board of Health. (2011). *Brain Injury - A Health Technology Assessment*. Denmark: National Board of Health, Danish Centre of Health Technology Assessment (DACEHTA).

increasingly be seen as being further emphasised by the client-centered strategy which in effect is seeking to bring about 'top-down' integration.

This leads us to propose a characterization of the existing service delivery system – at least as we have observed it in this pilot study - as a tension between the 'top down' integration being sought through institutionalised means to bring about more client-centred care with the existing 'bottom up' integration through informal means (seemingly more prevalent in the non-compensable sector) that necessarily emerges as some segments of the client population seek to 'joint things up' for themselves. The service providers in a sense are caught between these two modes of integration (Figure 5.2). In our view, the challenge in developing a new service model of the compensable sector is to find a way of combining 'top down' integration with a nurturing of 'bottom up' integration amongst compensable clients and their support networks. This would enable an improvement in overall service co-ordination, especially in the critical phase of service delivery (and critical junctures within it such as the interface at client transitions between health and social care) where the policy and strategies of service resourcing and commissioning are translated into actual client experience and which in turn effect client outcomes.

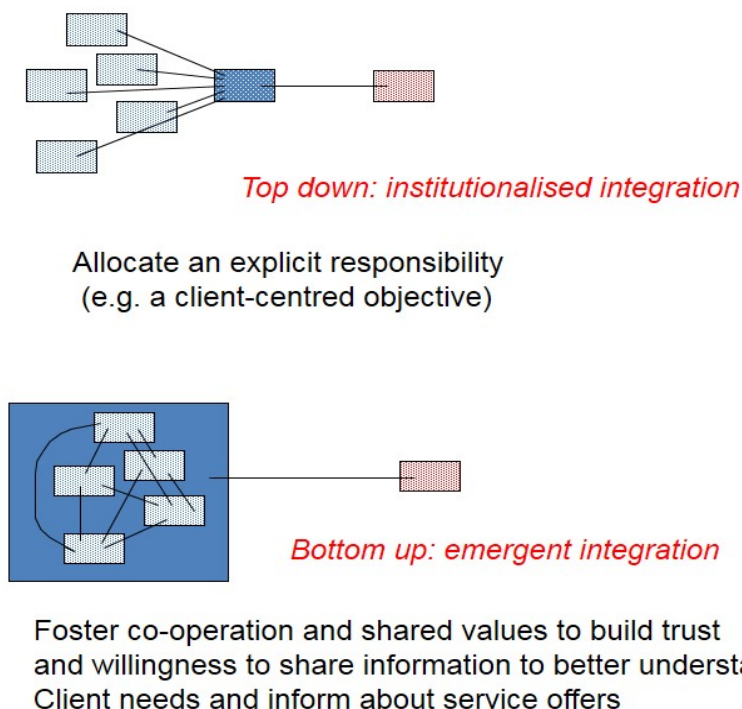
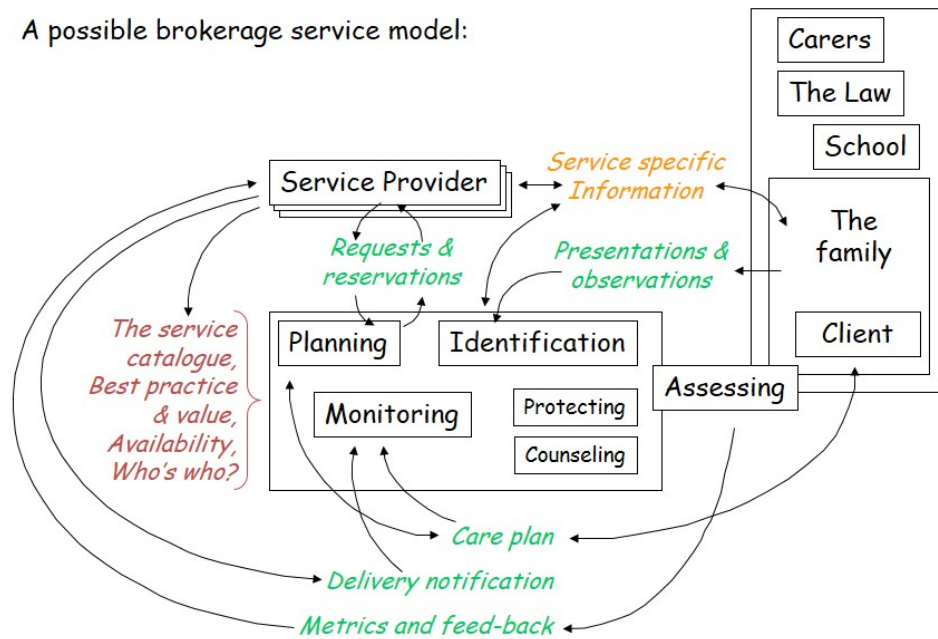


Figure 5.2: Top Down and Bottom Up Integration

A possible brokerage service model:



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Figure 5.3: A Service Model Architecture

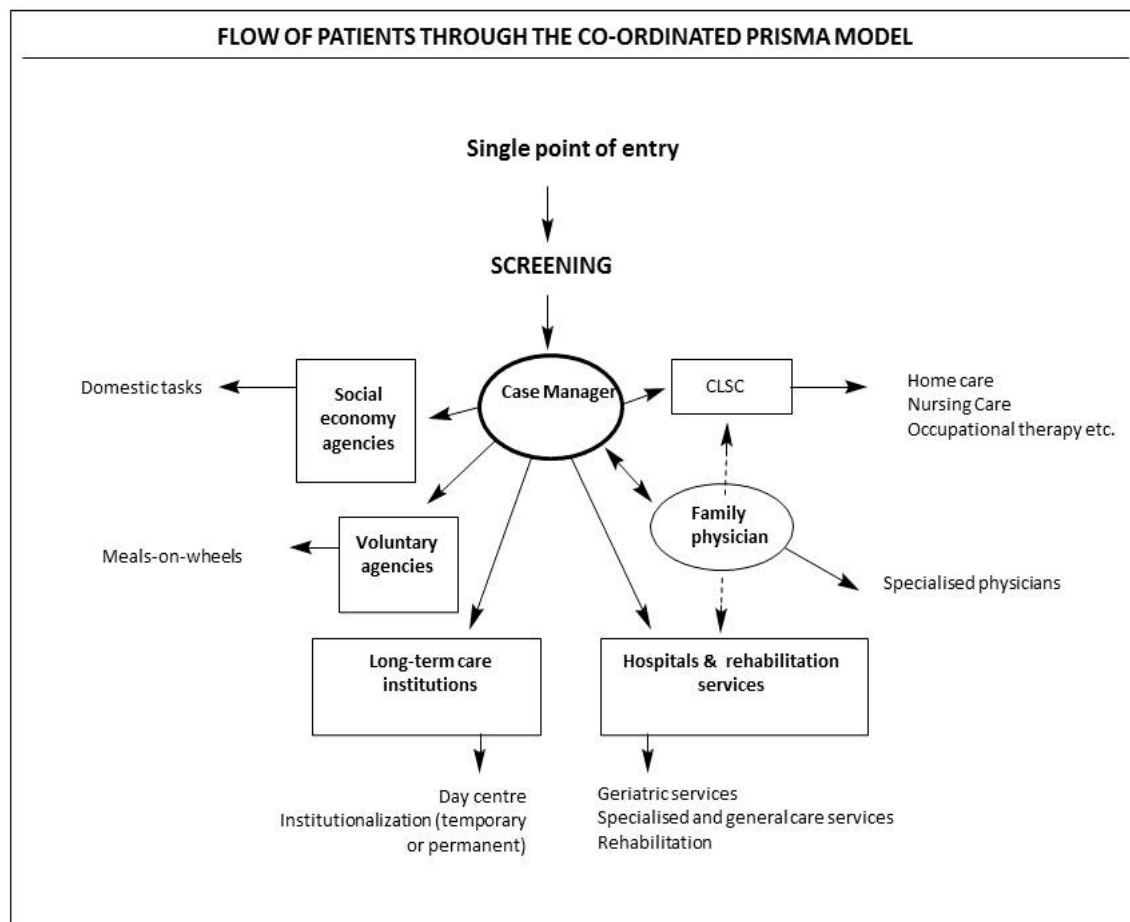
Box 5.2 and 5.3 provide other examples of integration models in practice which may have relevant insights and applications. Figure 5.3 provides an excerpt from a graphical representation of service modelling architecture developed in the UK by the public service innovation group within the Centre for Knowledge, Innovation, Technology and Enterprise (KITE) at the University of Newcastle upon Tyne. Service models combine informational and organisational elements. Service innovation, they argue, involves an architectural process involving the decomposition and recomposition of these components to determine how rights, roles and responsibilities and the relationships and conversations embedded within them might be (re-) allocated across a system of service commissioning, delivery and evaluation. The figure is a projection of some of the architectural features of a possible brokerage service model.⁵⁰

⁵⁰ We are grateful to Mike Martin and Rob Wilson of KITE for permission to reproduce this exhibit (<http://www.ncl.ac.uk/kite/>).

Box 5.2: PRISMA: A Canadian Model of Integrated Service Delivery System^{51,52,53}

PRISMA is a Canadian example of the integration of service delivery for improving efficacy and efficiency of health care systems, particularly for patients with multiple needs and complex interactions with many professionals and organisations (in this case older people).

The PRISMA model comprises six components; 1) co-ordination between decision-makers and managers at regional and local levels 2) single-point of entry, 3) case-management, 4) individualized service plan 5) single assessment instrument coupled with case-mix management system 6) a computerized clinical chart. All six elements of the model were deemed to be important in improving co-ordination between various service providers. This is depicted in the diagram below.



Evaluation of the PRISMA model has shown clear benefits for clients such as decreased frequency of functional decline, improved satisfaction and empowerment and for the health care system, fewer visits to the emergency room and hospitalization.

⁵¹ Hébert, R., Durand, P.J., Dubuc, N., Tourigny A and the PRISMA Group (2003) Frail elderly patients: new model for integrated service delivery. *Canadian Family Physician Journal*; 49:992–7.

⁵² Hébert, R., Dubois, M.F., Raïche, M., Dubuc, N., & The PRISMA Group (2008) The effectiveness of the PRISMA integrated service delivery network: Preliminary report on methods and baseline data. *International Journal of Integrated Care*, 8, 1 – 15

⁵³ Hébert, R., Veil, A., Raïche, M., Dubois, Marie-France, Dubuc, N., Tousignant, M. and the PRISMA-Estrie Group (2008) Evaluation of the implementation of PRISMA, a Coordination-type Integrated Service Delivery System for Frail Older People in Quebec, *Journal of Integrated Care*, 16(6).

Box 5.3: Danish National Service Delivery Model for Treatment and Rehabilitation of Patients with Severe Acquired Brain Injury

In Denmark a standardised treatment approach has been developed to ensure early, intensive interdisciplinary interventions for ABI patients which it is believed significantly improves client outcomes. Two specialised rehabilitation units, each with half the country as their catchment area, were established in 2000. Some of the features of this centralised service delivery model are:⁵⁴

- *Intensive interdisciplinary rehabilitation:* On admission a team of different specialists including a physician, a neuropsychologist, a nurse, a physiotherapist, an occupational therapist, a speech therapist, and a social worker is assigned to a patient. One of these well-educated staff acts as coordinator. After initial examination of the patient by the expert team and a meeting amongst the team, the patients' relatives, and, if possible, the patient, a comprehensive care plan is established.
- *Increased involvement and cooperation of family members:* Relatives are involved in the treatment of the patient from the early stages. They help the expert team about the patient's life and habits before the accident. They are also informed about the examination results and rehabilitation plan and methods using for rehabilitation.
- *Continuous review and update:* patients are assigned to a fixed physician, as much as possible. Every four weeks a meeting is held amongst the team and the relatives. If an incident happens during this time, an urgent meeting is been set up.
- *Follow up after discharge from intensive rehabilitation:* a meeting or two among a social administration, a representative from Brain Injury Council, relatives and, if possible, the patient will set up to discharge the patient if he or she is ready to go home and there is no progress during three months of intensive rehabilitation. During three years after discharge, patients readmitted every six months to assess their level of improvement and update their care plan.
- *Establishing a resource centre:* to systematically collect, analyse and share knowledge about ABI. The centre produces reports and educational programs for different audiences such as governmental departments, counselors, care providers, family members and relatives of the patients.
- *Collaboration:* with specialised education institutions and vocational rehabilitation

⁵⁴ Engberg, A. W. (2007). A Danish national strategy for treatment and rehabilitation after acquired brain injury. *The Journal of Head Trauma Rehabilitation*, 22(4), 221-228.

5.4. Designing Digital and Assistive Technologies to Support Service Improvement and Innovation

There is abundant evidence from health and social care sectors – and public service more generally - in Australian and beyond that if the deployment of digital and assistive technology is to be effective in meeting complex care needs, then their deployment needs to be led by innovation in service models and that change should not be technology-driven. However, this requires many of the cultural, institutional and other barriers to such change to be addressed. A key element of this is the development and application of methods and approaches used to elicit and understand the requirements of both clients and service providers and then to engage them in the design, development and application of solutions - many regard co-design and co-production as having a central role in such a process.

Many studies have discussed the utilization of technologies and possible influences on services and outcomes in the health care sector. Ní Scanail et al. discussed the approaches to tele-monitoring in health care, which involves a variety of sensor and information and communication technologies (ICTs), and pointed out that it can be used to monitor the health status of elderly and chronically ill patients in their own homes, by providing continuous quantitative data which can indicate an improvement of deterioration in a patient's condition.⁵⁵ In Sweden, the National Board of Health and Welfare has recognised the potential for modern technology to make life easier for family carers and the cared-for persons.⁵⁶ Likewise, the UK Audit Commission addressed that assistive technologies could help older or disabled people to live independently and safely at home.

There is evidence from a survey on patients with ABI in the US that suggests that clients want to access new technologies, especially to support services which could assist them with improving memory, attention, problem-solving abilities and activities in their daily life. The most frequently endorsed benefit of technology enabled forms of care, e.g. tele-rehabilitation, is the reduction in feelings of isolation and improvements in clients' ability to learn about the medical and cognitive aspects of their injury.⁵⁷ The potential positive impacts of adopting new technologies have also been evidenced in other contexts. For example, a report by the UK Audit Commission showed that assistive technologies can help older or disabled people to live independently and safely at home.⁵⁸

The potential benefits of tele-health and tele-care services are much debated and raise significant issues in relation to consent, privacy and confidentiality.^{59, 60} In

⁵⁵ Ní Scanail, C., Carew, S., Barralon, P., Noury, N., Lyons, D., & Lyons, G. M. (2006). Review of approaches to mobility telemonitoring of the elderly in their living environment. *Annals of Biomedical Engineering*, 34(4), 547–563.

⁵⁶ Magnusson, L., Hanson, E., & Nolan, M. (2005). The impact of information and communication technology on family carers of older people and professionals in Sweden. *Ageing and Society*, 25(5), 693-713.

⁵⁷ Ricker, J. H., Rosenthal, M., Garay, E., DeLuca, J., Germain, A., Abraham-Fuchs, K., & Schmidt, K.-U. (2002). Telerehabilitation needs: A survey of persons with acquired brain injury. *The Journal of head trauma rehabilitation*, 17(3), 242-250.

⁵⁸ Audit Commission. (2004). Assistive Technology. UK

⁵⁹ Scanail Scanail, C. N., Carew, S., Barralon, P., Noury, N., Lyons, D., & Lyons, G. M. (2006). A review of approaches to mobility telemonitoring of the elderly in their living environment. *Annals of Biomedical Engineering*, 34(4), 547-563.

general, the view has been that tele-health should be considered as an adjunct to traditional clinical service delivery and as a complement to and not replacement for face-to-face care. Research in aged care has highlighted the benefits of relatively 'low-tech', call centre based, 'tele-accompany' services in providing continuity of experience in the delivery of care, combatting feelings of isolation where clients live alone, and providing a means of brokering services to meet client needs and requirements.⁶¹

One of the authors of this report has been engaged in European research which explored how such tele-accompany services might be augmented and enhanced by tele-care technologies. A key finding of this research was the importance of co-design and co-production involving service providers (in this case health care and social care professionals and practitioners) and service users (in this case older people, their families and support networks) in the active re-design of the service environment. This involved the design of a tele-care platform which had sufficient infrastructural characteristics to allow it to be re-purposed and re-scaled in the face of changing needs, demand and policy requirements.⁶²

One important aspect of this research was the attempt to engage both service providers and service users in a process of co-design and co-production of a new service model. In general co-design and co-production have become a major means through which public service re-design and innovation are pursued in a variety of contexts.⁶³ Whilst predominantly focused on service re-design – for example personal budgets and self-directed care⁶⁴ - it has been argued that the approach can also be extended to engaging user communities in the design of technological and, by the same token, physical environments.⁶⁵ Clearly co-design and co-production present very specific and difficult challenges in the case of TBI and SCI clients. However, as the ISCRR co-design workshop which launched the SmILE project demonstrated, these are far from insurmountable.

⁶⁰ Magnusson, L., Hanson, E., & Nolan, M. (2005). The impact of information and communication technology on family carers of older people and professionals in Sweden. *Ageing and Society*, 25(05), 693-713.

⁶¹ Ricker, J. H., Rosenthal, M., Garay, E., DeLuca, J., Germain, A., Abraham-Fuchs, K., & Schmidt, K.-U. (2002). Telerehabilitation needs: A survey of persons with acquired brain injury. *The Journal of head trauma rehabilitation*, 17(3), 242-250.

⁶² McLoughlin, I.P. et al 'Hope to Die Before You Get Old' Public Management Review, 2009. <http://www.eldes.eu> and <http://www.spes-project.eu>.

⁶³ See e.g. Alford, J. 'Why do public sector clients co-produce?', *Administration and Society*, 2002.

⁶⁴ See e.g. Parker, S and Parker C (eds) *Unlocking Innovation: Why citizens hold the key to public sector reform*, NESTA, 2011.

⁶⁵ See e.g. Special edition on communities and co-production of *Information, Communication and Society*, 2012; ACTIVE Consortium, *The Role of Telecare in Meeting the Care Needs of Older People*, 2013.

6. Conclusions and Recommendations

TAC has embarked on a strategy to make its service delivery to be more client-centred in order to support independent living for its clients in order to improve performance in scheme viability, client experience and client outcomes. This pilot study has scoped some of the options and possibilities for developing a better coordinated, higher quality system of care for those unfortunate enough to sustain ABI or SCI injuries. We have focused in particular on the potential improvements in the management of human resources, business processes and the management and sharing of information in the delivery of services to clients. Our findings confirm that there are many deficiencies, barriers and constraints to achieve a more client-centred approach which is able to support independent living. This is the case in particular relating to the skills and limited professionalisation of the paid care workforce, the resourcing and organisation of the workforce, the fragmented nature of the existing care delivery system and the limited scope and resources available in the past to seek service innovations, especially those supported by the adoption of new technologies.

To address these issues, we identify, by way of recommendations, a number of action research areas intended as interventions to co-design and co-produce improvements and innovations in service delivery. These have as their collective aim the identification, trialing and evaluation of the key elements of a new service delivery model better able to support the innovations in care and physical environments at the heart of supporting client independence. These recommendations focus in particular on specifying in more detail what is required for the development of a 'one stop' service model based on the principles of brokerage and intermediation allied to improvements in: the efficiency and effectiveness of the management of human resources, the management of quality and service improvement, in particular in relation to partnership and cross-agency collaboration, and the management of information and deployment of assistive technologies to support long-term care.

These areas of service improvement and innovation interface with developments in models and practice of client-centred care and changes to the architecture and design of the physical environment in which care is delivered.⁶⁶ Indeed, whilst improvements and innovation in these areas are likely to yield benefits, we argue that these will be constrained if the management and organisational issues that currently affect the existing fragmented service delivery system (as we identified in this pilot project) are not also considered. In short, if TAC's long-term strategic and performance objectives are to be met, we suggest that all three of these areas now need to be treated in a holistic and system level manner and not in isolation.

In this section we also structure our findings in the context of our four research objectives. We outline a number of interventions in the form of action research to improve and innovate the way in which human resources, service delivery and information might be better organised and managed. The potential improvements and innovations we identify would involve co-design and co-production with services providers, clients and their networks and other stakeholders. In exploring the implications of our findings, it should be borne in mind that they represent preliminary

⁶⁶ See Murray et al Design Contributions to Life Time Care, ISCRR, Report no: C-M-13-066, 2013.

outcomes from a pilot study intended to scope possibilities and options for service improvement and innovation. Our recommendations therefore take the form of potential lines of further study and action research in relation to:

- workforce development
- business process improvement
- technology-assisted service design and innovation

We also indicate the possible benefits to TAC in terms of scheme viability, client experience and client outcomes. In keeping with TAC requirements, our recommendations are mainly focused on things that might change behaviours (e.g. of the paid workforce and service managers), organisational level improvements and innovations amongst service providers, and the contribution that information systems and assistive technologies can make in supporting long-term care. Many of these initiatives can have more immediate impacts and generate significant improvements in the long-term. Others, of course, require more system level changes if they are to provide sustainable solutions in the delivery of long-term care.

6.1. Recommendations for Skills, Competencies and Development Requirements

Our findings suggest that there are immediate requirements for interventions that can improve the capability and quality of the workforce and the managerial capacity and resources available to manage the delivery of care in a more cost-effective, high quality and client-centred way.

We would recommend action research interventions in the following areas:

➤ *Skills and training*

- The exploration of systematic audits of skills and training needs analysis of PSWs to help service providers more accurately identify the skill gaps which are likely to constrain a move to more client-centred care and to enable more targeted investment in on-going training and skill development.

➤ *Capacity building*

To support the development of sector-wide strategies through actions and initiatives intended to improve the capacity of the workforce to deliver new models of care, including:

- The identification and development of frameworks of key PSWs' attributes that demonstrate commitment to the values and practice of client-centred care, which in turn could be embedded in the recruitment practices of service providers;
- The identification of gaps in existing service provider policies and procedures to promote workplace safety and employee wellbeing;
- The refinement of induction training and establishing more effective continuing professional development programs;
- The development of career progression pathways linked to the attainment of formal vocational qualifications; and

- The systematic improvement of supervisory practices including rostering, performance evaluation processes and reward systems to develop high performance work systems.
- *Human resource management and high performance work systems*
 - Work with service providers to improve HR/information systems to reduce manual workload and to improve information provision and business processes with regard to key efficiency issues such as scheduling and resourcing to better meet client needs
 - Work with service providers to develop initiatives to design more team-based forms of working appropriate to a mobile care workforce and identify training and other developmental measures to improve motivation and build more effective work teams, facilitate knowledge sharing and improve employee commitment. This might involve, for example, the trial forms of mobile team-working and evaluating the effectiveness in meeting client needs and improving operational performance. The aim would be to establish more continuity and improving the quality of care as experienced by home-based clients.

6.2. Recommendations for New Service Delivery Models

Our findings suggest that achieving the objectives of a more client-centered approach will ultimately require new service models to be developed and adopted by the multiple agencies in the frontline of delivering care services to clients. Starting to re-design the current care service delivery model might be addressed through the following recommendations, each involving interventions to co-design with service providers, that aim to demonstrate improvements and innovations, which would have impacts and benefits on key TAC KPIs:

- Trial and evaluation of the potential benefits of lean thinking and continuous improvement methodologies to improve intra-organisational operations and quality procedures. Techniques that might be applied and tested include value stream mapping, activity based costing, cost reduction, and quality improvement activities such as 'quality circles'. Interventions might focus on one or more care provider organizations as 'demonstrators' or 'worked examples' of such practices which might then be diffused more widely across the sector through awareness campaigns and sector specific training and development activities.
- Work with primary medical care services, secondary rehabilitative services and therapeutic services to improve service co-ordination at the critical acute phase to provide a less confusing system for clients and which helps them navigate more smoothly through different service offers and providers. Such an approach might be developed at the sub-regional level to provide a 'best practice' model of more integrated service delivery that might be adopted elsewhere.
- Begin work on specifying the architecture of a 'one-stop' service model based upon the principles of brokerage and intermediation to deliver the objective of 'one client, one contact, one plan'. At the core of this work would be facilitative actions to support the development of partnership and cross-agency collaboration necessary to provide a more 'joined-up' and 'seamless' experience

for clients. This research could deploy tools and resources developed elsewhere to facilitate and develop cross-agency working.⁶⁷

6.3. Recommendations for Service Innovation and the Adoption of New Technologies

Our findings suggest a clear need amongst service providers and clients to explore how a more technology assisted model of long-term care can be developed. However, if this is to be effective in meeting needs, then there is also a need to improve the methods and approaches used to elicit and understand the requirements of both clients and service providers in the first place. We would recommend the following:

- Exploring with clients and service providers the value that might be provided by new channels to communicate with TAC and care providers over service availability, use and evaluation (e.g. web-based systems, tele-accompany services, tele-care and rehab, on-line service directories) to complement and support more efficient attendant care. Elsewhere it has been shown that, in the case of information provision for patients and their carers after stroke, information provision in the form of leaflets, booklets and manuals is not effective and has no effect on quality of life for clients and their informal caregivers, perceived health status and improvement of the clients' mood.⁶⁸
- Clarifying within the system of care and the service delivery model as a whole the informational requirements (i.e. roles, relationships, governance) required to support a more co-ordinated service delivery and information sharing across service providing agencies. This would be related to the service architecture and partnership building activity identified above.
- Evaluating the potential gains in terms of efficiency and information management by service providers and their workforce of mobile technology (M-care), for example, to support better workforce management and client relationships. At least one of the care providers in the pilot study was keen to explore the potential of tablets and similar mobile devices for more effective management of paid care workforce and the monitoring of client satisfaction with the quality of services delivered.

6.4. Benefits and Impacts

The above recommendations, if pursued, can be anticipated to bring a number of impacts and benefits in terms of TAC's strategic KPIs. We itemize what we see as the most significant of these bearing in mind the observation of one of the managers we interviewed who made the point that in the end experience, outcomes and performance "*starts with the client and the carer*" but the impact of their relationship "*reaches far and wide.*" (M1-6)

⁶⁷ See e.g. www.fame-uk.org (a project sponsored by the UK government to transform the delivery of local services through partnership working).

⁶⁸ Forster, A., Smith, J., Young, J., Knapp, P., House, A., & Wright, J. (2001). Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews*.

6.4.1. Scheme Viability

- More effective use and deployment of human resources to reduce service delivery costs of attendant care;
- Improvements in the use of attendant care resources by providing paid support workers with more timely and accurate information and better assessment and recording tools;
- Reductions in care delivery agencies' costs through more efficient and less wasteful business processes and improvements in service quality;
- Reductions in scheme costs arising from length of stay in hospital;
- Creation of a full picture of client needs for service providers through improved service co-ordination;
- Enhanced efficiency and sustainability across the care system;
- Improvements in aggregate information flows to inform service commissioning and resourcing plans and the strategies of service providers; and
- Improvements in the management of information in care organisations by increasing accuracy and reliability, efficiency from reduced redundancy, and timeliness and ease of use and access.

6.4.2. Client Experience

- Improvement in client satisfaction and well-being from experiencing more 'joined-up' care services as they are better able to achieve their goals;
- Increased opportunity for clients to self-manage their care plans and be more engaged in their execution;
- More seamless, coordinated care and appropriate information on-time enabling clients to be able to interpret correctly, communicate effectively with each other and with care providers in order to decide in a more informed way about what is best for them;
- Reduced feelings of being left alone to deal with problems by being provided with informational and other assistive resources to better enable the planning and customization of care; and
- Improved likelihood of client satisfaction with paid care due to improved skills and consistency of service, improving the quality of support provided.

6.4.3. Client Outcomes

- Long-term benefits of better co-ordination and integration of service delivery enabling greater independence and faster recovery;
- Improved self-management by clients through access to complementary 'virtual' support services;
- Empowerment of clients to self-manage care and support for long-term increases in independence;

- Long-term improvements due to reductions in risk, mistakes and improved capability of paid care workers to work within care models based on supporting independent living; and
- Long-term improvements due to reductions in risk, mistakes and improved capability of paid care workers to work within care models based on supporting independent living.

Achieving the above benefits and impacts will require a significant change with respect to how those with SCI and TBI are cared for and how their changing needs are managed. This will include developing new skills and competencies amongst care providers and their workforce and the adoption of new management practices; the use of digital/assistive technologies in attendant care, and appropriately designed care facilities and living environments. All of these changes are predicted on the development, adoption and diffusion of new service delivery models. Bringing about such innovation will require close coordination and engagement amongst key stakeholders as they develop new forms of collaboration, partnership and patient-centred care.

6.5. Suggested Research projects

Below we present an outline of three major projects that we would propose to undertake as part of the second phase of funding. We are currently developing a fourth project proposal focusing on mobile technologies for paid care workers that would be led by Professor Peter Brooks from the University of Melbourne in collaboration with ourselves and other relevant researchers.

6.5.1. PROJECT 1: Skills training and development for the care workforce in the Compensable Sector

This project will address the skill needs for the care sector in order to enhance the quality of care services and the satisfaction and well-being of both the clients and the care workforce.

It involves:

- producing a skills audit of the care workforce through working together with a number of participating care organisations;
- identifying a set of skills needed for the delivery of effective care services;
- designing appropriate human resource interventions to develop those skills; and
- identifying good practices and areas for improvement in human resource management (HRM) practices and analysing how the skill training and development can be an area for the overall improvement of the HRM system.

Process:

- Ethnographic immersion to understand disability care context and needs (for both the client and the carer);

- Action research through a series of facilitated workshops with stakeholders (e.g. clients and their family, managers of care service provider organisations, and carers at various level and functional area) to identify skill gaps and development areas;
- Co-develop a range of skill training and development intervention tools, including for example: on-line learning and sharing of best practices, situational learning, and problem-based reflective seminars and other fora to share experiences.

Deliverables:

- A skill repertoire for the care workforce;
- A set of training and development workshops/programs/models that can be tailored for specific organisations;
- Examples of good HR practices that can be shared by other organisations in the care industry;
- Identification of areas of HRM that require improvement in order for the skill training and development to become more effective as an integral part of the HRM;
- Report/published papers on research findings in high profile academic and practitioner journals;
- Participation of Monash research team members in facilitating training and development workshops; and
- Participation in Monash University CoDesign Hub.

6.5.2. PROJECT 2: Process Improvements in Disability Care in the Compensable Sector

This project will focus on achieving improvements in business processes within care provider organisations and across the compensable disability care sector. It will apply Lean thinking and continuous improvement methodologies (e.g. Six Sigma) to achieve dramatic improvements in cost, quality, safety and speed of delivery in an effective and efficient manner.

It involves:

- Increasing awareness and leadership capability amongst senior management to lead major change programs based on Lean Six Sigma.
- Increasing knowledge and capability amongst staff to undertake process redesign using Lean Six Sigma methodologies. This will involve education and training through workshops for staff at all levels.
- Mapping current processes to highlight deficiencies in existing systems and building a sense of ownership and accountability for developing, operating and managing processes.

- Developing appropriate performance indicators to measure improvements in processes.
- Undertaking pilot projects to demonstrate the application of Lean Six Sigma in process redesign/improvement.
- Identifying the critical factors that impact on project success and the skills and competencies necessary for undertaking process improvements.
- Developing implementation strategies for sector-wide implementation of Lean Six Sigma.

Process:

- This project will initially involve a number of workshops to: (i) raise awareness and leadership capability amongst managers, and (ii) to build skills and competencies amongst staff to undertake Lean Six Sigma projects.
- Action research where Lean Six Sigma methodologies will be applied in partner organisations and pilot projects will be completed. Co-development of relevant performance indicators and key skills and competencies necessary for staff all different levels to achieve project outcomes.
- Mentoring and facilitation of major projects undertaken by care provider organisations. Sharing of best practices across the sector through seminars and publications.

Deliverables:

- Lean Six Sigma training material and methodologies for its application in the disability care sector.
- Development of critical success factors and performance measures for applying Lean Six Sigma in the disability care sector.
- Report/published papers on research findings in high profile academic and practitioner journals;
- Participation in Monash University Co-Design Hub.

6.5.3. PROJECT 3: Innovative Service Architectures for Co-ordinating Client-centred Care Services in the Compensable Sector

This project will co-produce a reference service architecture that will allow service commissioners, providers, support workers, clients/families and other stakeholders to rethink rights, roles and responsibilities in the provision of client-centred care and to thereby make effective decisions and choices concerning the design, deployment and use of digital and assistive technologies within appropriate governance frameworks for sharing information in a timely, appropriate and safe manner.

It involves:

- Adapting and building upon a ten year program of research conducted at Monash's strategic partner University of Newcastle upon Tyne in the UK which has focussed upon the problem of service integration and the co-production service architectures.
- Ethnographic research to map the existing service delivery system, understand the user experience (service provider and client) and elicit their needs and requirements, and identify the institutional and cultural barriers and constraints in moving towards a more client-centred co-ordinated service model.
- Action research through a series of facilitated workshops with stakeholders to elicit needs and requirements and develop a common understanding and language of the issues and challenges of service co-ordination and being client-centred and of the kind of solutions which might work in the context of joining-up care services in the compensable sector.
- Co-production of a reference architecture specifying organisational and informational requirements of a more co-ordinated system of care and associated governance frameworks which can be the basis for service innovation and improvement.
- Evaluation and bench-marking of the proposed service architecture against best practice service models through a representative sample of international case studies and possible pilot innovations in the compensable sector in Victoria.

Process:

- Ethnographic immersion to understand user context and needs; action research with stakeholders to co-produce service models and match these to user needs; development of a reference architecture; engaging the expertise of experts in service architecture modelling and innovation at the University of Newcastle involving international travel which will also assist evaluation and benchmarking.

Deliverables:

- Reference Architecture for Co-ordinated, Client-Centred model of care service
- Report/published papers on research findings in high profile academic and practitioner journals
- Participation in Monash University Co-Design Hub.

7. Appendix

Appendix I: Participants Coding

Table 7.1: Interviewee Participants Coding

Organisations	Managers	PSWs	Clients	Client Members	Family
CP1	M1-1	C1-1	CL1-1	-	
	M1-2	C1-2	CL1-2	-	
	M1-3	C1-3	CL1-3	-	
	M1-4	C1-4	-	-	
	M1-5	C1-5	-	-	
	M1-6	C1-6	-	-	
	M1-7	C1-7	-	-	
	M1-8	C1-8	-	-	
CP2	M2-1	C2-1	CL2-1	CF2-1	
	M2-2	C2-2	-	-	
	M2-3	C2-3	-	-	
	M2-4	-	-	-	
CP3	M3-1	C3-1	CL3-1	CF3-1	
	M3-2	C3-2	CL3-2	-	
	M3-3	-	-	-	

Table 7.2: Focus Group Participants Coding

Organisations	PSWs		Managers	
CP1	FG1-1	FG1-1-A1	FG1-2	FG1-2-A1
		FG1-1-A2		FG1-2-A2
		FG1-1-A3		FG1-2-A3
		FG1-1-A4		FG1-2-A4
		FG1-1-A5		FG1-2-A5
		FG1-1-A6		-
		FG1-1-A7		-
CP2	-	-	FG2-1	FG2-1-A1
				FG2-1-A2
				FG2-1-A3
				FG2-1-A4
CP3	FG3-1	FG3-1-A1	FG3-2	FG3-2-A
		FG3-1-A2		FG3-2-A1
		FG3-1-A3		FG3-2-A2
		FG3-1-A4	FG3-3	FG3-3-A
		FG3-1-A5		FG3-3-A1
		-		FG3-3-A2
Regional alliance agencies	-	-	FG-A1	FG-A1-A1
				FG-A1-A2
				FG-A1-A3
				FG-A1-A4
				FG-A1-A5
				FG-A1-A6
Funding agency	-	-	FG-A2	FG-A2-A1
				FG-A2-A2
				FG-A2-A3
				FG-A2-A4
Government agency	-	-	FG-A3	FG-A3-A1
				FG-A3-A2
				FG-A3-A3

Appendix II: Interview Guide – Executives/Managers

1. Could you please tell us a little bit of the organisation's background, e.g. how long has the organisation been established? What is the ownership of the organisation?
2. Where is the funding/revenue coming from? What is the total revenue funding budget of the business?
3. Who are the organisation's main clients (corporate and individual)? How are individual clients (i.e. those who require care) allocated to the organisation, or how does the organisation obtain these clients?
4. How long does a contract typically last?
 - a. With corporates?
 - b. With individuals?
5. How are the contractual relationships between the organisation and the client managed? What governance/monitoring mechanisms are in place? What are the key performance indicators (KPIs)? What are the reporting requirements and channels? Is there a service level agreement? If so could we have copies please?
6. In addition, how does this organisation develop and maintain a good relationship with the clients beyond the contractual agreement?
7. What is the overall strategy of the organisation? What are the key business challenges?
8. What is the organisational structure?
9. What is the size of the organisation in terms of total number of staff employed?
10. What types of employment contracts do the care workers hold? What are the demographic characteristics of the workforce? E.g. ratio of full-time vs. part-time, age, gender and ethnicity profile, educational and occupational qualification, etc.
11. What are the sources of recruitment for the care workforce? Is there a recruitment and retention problem? If so, why?
12. Is there a recruitment and retention strategy? Could we have a copy please?
13. (If not already apparent) to what extent the care workforce employed on a casual employment or a continuing basis?
14. What level of qualification do you look for in recruiting carers?
15. What are the core competencies that you look for in recruiting carers?
16. Do you provide training to your care workforce? If so, what type of formal training is provided? (eg. which qualifications do you train for) What type of non-formal

training is provided? (eg. in-service training in company procedures) Do you monitor informal training/ (eg through mentoring?)

17. How many hours of training would you provide each year to each employed carer? Is training conducted during the shift or after working hours? Are employees paid to attend training?
18. How effective are these training arrangements? What are the key outcomes for the business?
19. What is the level of enthusiasm for the workforce to participate in the training? What percentage of your care workforce participates in training each year?
20. How is the care work organised? E.g. shift patterns, visit schedules, methods used for matching carer with clients, etc.
21. Are any of the care workers covered by awards or enterprise bargaining agreements (EBAs)? Which awards or enterprise bargaining agreements (EBAs)? Could we have a copy please?
22. Are any of the care workers organised by unions? Which unions?
23. How are the day-to-day carer-client (those receiving care) relationship managed?
24. What are the key challenges in managing this relationship? Please give examples.
25. In what ways technologies are used to facilitate the care provision/care service delivery? How effective are they? What may be the impact/implications for the care workforce and the clients/their family carer?
26. How is the performance of individual care workers managed? What are the measurement criteria? How important is client feedback to the performance evaluation of the care staff?
27. What is the business model adopted now by the organisation? What major changes have taken place in the last five years, if any?
28. Do you provide different services to different customer segments?
29. What have been the main driving forces /pressures for the changes? What have been the impacts of these changes to the organisation, the care workforce and the clients/family?
30. What changes to the organization and its business model do you anticipate would take place in the near future?

Appendix III: Interview Guide – PSWs

1. How do you perceive your roles in the organisation and this industry?
2. What attracts you to this job?
3. Why do you want to help people in need?
4. What training or qualifications have you had specifically for this job?
5. What qualities and skills do you think are needed for a carer's role? Do you believe that you have the skills you need to do the current job?
6. What skills gaps do you feel you have? How would you like to develop these skills?
7. Do you work nights or weekends?
8. Do you have any other jobs? If yes, what and why?
9. Do you find your job physically demanding? If yes, please provide example.
10. Do you find your job emotionally or psychologically demanding? If yes, please provide example?
11. How do you manage a grumpy or difficult client? Please give examples
12. Can you describe a difficult moment at work? What happened? How did you handle it?
13. Have you experienced emergency situations at work where you had to make a quick on the spot decision? If yes, please describe what happened?
14. Do you have conflicting demands at work? If yes, can you please describe how you handle those situations?
15. Do you work in a team or alone?
16. Do you feel supported at work?
17. Have you been trained on how to deal with job-related stress?
18. Who do you go to for support when you are over-whelmed by your work demands?
19. What kind of support do you receive when you feel over-whelmed at work?
20. What specific training will benefit you?
21. Are you offered incentives for attending training and development programs?
22. What is more important to you? Money or fulfilling work?
23. Do you feel this job pays well?
24. Do you find this job fulfilling?
25. What do you do to de-stress?
26. What are your suggestions for improvement to your job?

27. Do you see advancement in your career in this field?
28. What is most rewarding about your work?
29. What is most unappealing about your work?
30. Do you believe in a religious or spiritual faith or practice? Does this help you?
How?
31. Where do you see yourself five years from now?
32. Do you believe that using technology will help you for your day to day tasks?
33. What sort of technologies do you use to provide services?
34. Do you think the services provided for clients can make them live more
independently?
35. How do you think the quality of service provided for clients could be improved?
Any suggestions to the organisation?

Appendix IV: Interview Guide – Clients/Family Members

Clients

1. Could you please tell us how life has changed since the incident?
2. Do you feel you can live a fairly independent life with all the support available to you? Tell us how?
3. How would you comment on the services received from the carer provider and support workers?
4. Are you able to use the computer and the internet? For what sort of activities like Email, chat, game, ...? How often do you use them?
5. What kind of technologies that you believe is useful to manage your injury and life style activities? Like reminders, interactive planning calendars, alarms, teleconsoulting, telerehabilitation, telemonitoring,...
6. Out of everything the service provider does, what is the most valuable to you and the least valuable? What are your reasons for these answers?
7. Do you have any suggestions on how your needs can be better served?

Family members

1. How would you comment on the services received from the carer provider and support workers?
2. Do you use any kind of technology to assist your family member? What are the benefits and challenges of using technology in this context?
3. Out of everything the service provider does, what is the most valuable/invaluable element of the service provided?
4. Do you have any suggestions on how your/Client needs can be better served?

Appendix V: Focus Group Discussion Guide

1. How do you perceive your roles in the organisation and this industry?
2. Can you describe a difficult moment at work? What happened? How did you handle it?
3. Could you please describe a typical day that you work?
4. What would you do if a client complains? Some examples?
5. Do you believe that you have the skills you need to do the current job?
6. How do you think the quality of service provided for clients could be improved? Any suggestions to the organisation?

Appendix VI: Selected Quotes

Box 7.1: Respondent Views: Changing Context of Care

Changing Context of Care

PSWs

In response to a question on the opinion of how a carer (in an institutional setting) perceives the lives of a client be improved towards independence:

"...I would like the NDIS I think, they've got a new scheme. And I do not know whether they have got the funds for it or not or whether they are implementing it admittedly because it's going to cost a lot of money.... if they've got enough funds I think... if I think that's what the scheme is, yeah, they can have their own carer. They can live on their own. But that'll take a long time, because first of all they don't have the funds. And I think the government, also doesn't know what it's all about" (C2-2)

Managers

"It sounds great in theory and it's great that additional money is coming for people with a disability and mental health...How that's actually going to work when people manage their own money and are looking for bang for buck, we just don't know how that's going to look into the future." (M3-3)

"...And at a broad policy level we pushed very hard for the establishment of the National Disability Insurance Scheme and when people write the history of the National Disability Insurance Scheme you will find that [CP2] would have been the centre of that. And the history of that is when Kevin Rudd came to power, went to Canberra in the 20/20 vision and managed to get the concept of the NDIS up as one of the 20 great ideas for the century." (M2-2)

"...For me one of the things we have initiated in [CP2], for example, is a research in innovation framework which hasn't been implemented and the organisation is going to set aside, and I can say this for sure, set aside a million dollars over four years for research, which I think is pretty good for a small organisation. And so for me the purpose at different levels, so from the level of an organisation, my argument is, as I said to the board, if you want to be like, in light of NDIS, my argument is why would I choose [CP2] as a service, as my preferred service provider? So what makes us unique as you say in marketing, what is the unique value proposition? What makes us stand apart from the others?" (M2-1)

Box 7.2: Respondent Views: Staff Resourcing

Deployment of skills

Managers *"... if there's a client that's located within the northern suburbs, in my mind I know some of the clients that are at need or at risk, and knowing a little bit about them, so getting the proper briefing from the client services team about what the needs or requirements are, if the client's grumpy, if the client's happy, if the client has an overbearing mother or anything like that. It's just knowing could that person's personality work with that person or not. As my colleague says, we're like those relationship matches, because we are trying to match personal dynamics to the right person as well. So not every person is going to fit every client, (and) not every client is going to like every person. So sometimes you're not going to get it 100% correct but you can only do what I say is the best of your ability." (M1-5)*

PSWs *"... It's really tough for them to go from life without a disability to having your world completely upside down."*

"I think the client and all of us do (the carer-client match). I think the manager, the client and the carer. Because I think if there's somebody that we feel we don't want to work with we can always say to the manager and similarly with the client, if they say that, 'There's a carer, I don't want to work with that person' they speak to the manager. So the manager's like the lynchpin of that relationship between everybody." (FG3-2-A4)

Workforce turnover

Managers *"... looking at numbers last year, we probably had under 50% staff become retrained. That was last year. Before that it was higher. And again probably where that fail was the man power of actually getting it organised. Yeah, we have had some turnover of staff and it's quite a big project to manage basically ... if we get at least a 60 or 70% retrained that would be absolutely amazing. But I think we need to be realistic and if we get 50% of our staff retrained, even at least doing one course rather than two, that's still a good starting point because we're still refreshing their minds, basically and they're not just sitting there redundant." (M1-5)*

PSWs *"... In two and a half years, I learnt one thing, most of the people working in disability they are not happy with the system. Like especially ... they don't know exactly what is happening in the houses and they come and just show their bossiness and try to make changes, which are sometimes impossible. And another thing they are not happy with their pay scale ..." (C2-3)*

"No one is ever happy with it (wage) ... but that comes with disability... there is no money in disability ... it's not something you can promote to entice people to come in. It's hard work – not only physically draining – it can be emotionally and mentally draining. So, no, it's not glamorous, not everyone wants to do it." (C1-2)

Box 7.3: Respondent Views: Skills, Training and Workforce Development

Skills Training

Managers *"... At the moment we are conducting ABI training for behavioural needs. So we have started ... I call it a bit of a pilot because we have had not specific ABI training like dealing with complex behaviours and things like that and most training loosely covers ABI clients and things like that. But having it quite specific to ABI clients, that's probably our current pilot and then that'll become a regular thing on our training roster. So that was more so we want to gain feedback of whether it was beneficial, whether staff got anything out of it, whether they already knew this. Really just asking the whys, whos and wheres because there's no use in running a training if we assume they know it or we're assuming they should already know it or anything like that. So, and I believe that went quite well so that's going to become a regular occurrence." (M1-5)*

PSWs *"They prepare you for the types of people that you might encounter different, varying abilities and disabilities. On the OH&S side of things they don't necessarily delve in – while of course, manual handling and medication administration and all that sort of stuff and major OH&S issues – the emotional complexities that come along with it are also OH&S. Like I've come across people who become extremely attached to clients and families and vice versa and breaking down those boundaries of 'I'm here on a professional basis' ... that's a massive OH&S issue ..." (C1-2)*

"Occupational health and safety, is very important because unless you have that structure, we're dealing with people who do have an acquired brain injury. So there are some people who can get a little bit verbally and physically assaultive. So our background doesn't consist of psychology/sociology so we can't really pick up on certain signs of one's particular behaviours." (C1-8)

"... I've found is that for the most part, you do learn as you go and I guess that would be something that I would learn eventually. But it would be nice to know how to deal with it before I got there but it doesn't always happen that way." (FG1-1-A2)

Career development issue

Managers *"I think that there's some workforce development there in relation to therapists and more specialist people, rather than people that we might employ as well. Insofar as our workforce is concerned, in the first instance, and especially your PSWs as you were saying before, I'm not sure how we're going to manage that with disability care. The more individualised the service response is the more difficult it is to recruit and retain skilled and confident competent staff. And there's going to have to be a whole heap more work done in relation to developing our workforce and making sure that they're equipped to work with people with a range of disabilities. I really can't see the answer at this stage." (FG3-2-A1)*

PSWs *"I've met people who have been in the industry for like 20 odd years or so and still work in the industry as a carer." (C2-1)*

Box 7.4: Respondent Views: Work Roles and Environment

Isolation environment at work

Managers *"I think that's fairly common working in isolation." (M2-3)*

PSWs *"I try to come into the office as often as I can ... I live quite a while away ... but you sort of speak to people on the phone, apart from my supervisor who I have spoken to the whole time I've been here – but other people come and go in the office and every time I go in the office, it's like, 'I don't recognise anyone'. And then I'll get introduced and they go, 'Oh, I remember speaking to you on the phone'. But it's a very isolating work environment." (C1-4)*

We also asked the PSWs whether the organisations encouraged them to talk to other PSWs and whether there were any privacy issues if they exchanged experience. One interviewee said:

"There is privacy issue, definitely. But privacy issues are only an issue if you talk to another support worker who doesn't necessarily know your client and you tell them their full name and where they live and things. It also becomes more of an issue if you start to gossip about your client rather than actually saying, 'I am having difficulty with a certain issue'. But as far as the organisation goes, it's not encouraged or discouraged, it's not really spoken about." (C1-4)

Work-life balance issues

Managers *"I think I'm very fortunate that, again, my general manager is so skilled and knowledgeable and keeps an eye out. She looks after our welfare; she's terrific about work-life balance. Like, for example, when I have three weeks where we're working 10 hour days and they say, 'Oh I've got to do such and such I'll take a half day leave' and she'll say, 'Don't be stupid, just go.' She looks after us very well that way." (M3-3)*

PSWs *"... my coordinator is amazing ... and I've worked with some other coordinators in the past and it can feel a lot like that because they sort of don't understand why you can't do all of these extra shifts and, 'Surely it's an easy thing to go to the next client' and sometimes it's not. But I think the coordinator that I have at the moment, I know that I can call her up at any time and everything is just really too easy with her. Like not too easy but do you know what I mean? ... She's really understanding and really helpful with what to do so ..." (C1-3)*

Safety and emotional wellbeing issues

Managers *"A lot of the houses, especially with ABI, they can have a lot of really aggressive clients and we're there to look after them so you can't say, 'You're not allowed to do anything. You're not allowed to obviously punish or work in that sort of ways and neither do we want to.' But at the same time it's a very stressful environment to respond appropriately and not be frightened. So they're huge complications, especially when, and this isn't one of them, but they're BOC, what we call Behaviours of Concern, which is sort of an enthusiastic way of saying really quite aggressive, hostile people. So, yeah, so that's another OH&S." (M2-4)*

PSWs

"... (A) client ... I currently support also has an ABI and becomes quite over familiar with female support workers. I don't think they stress enough the safety and that, they don't give you the tools to handle someone who is trying to (sexually assault you)..." (C1-4)

"... to be quite honest, I feel that in the last two and a half years, I have really emotionally invested in a lot of my clients, to a point where they almost become like a second family. So when they get sick or something goes wrong, it makes me really stressed out. And because you spend so much time with these people, you're not supposed to form these bonds but these do happen and they know in the office that sometimes I see clients outside of work. And that's okay, but long-term, it's not a job I could see me doing for more than say five years because I'm just the type of person who gets too emotionally invested in my clients." (C1-4)

"... I look after clients with quadriplegia, muscular dystrophy, so every time they want to move their hands or something, you have to move them. So it's just constantly being up and about and doing things for other people means that when you come home, you're exhausted. And so, it's a physical strain but an emotional strain. And so, I think it's a good time for me to leave the industry because I'm still quite passionate about it and I still feel like I take good care of the people I look after, rather than me getting to a point where I am really resenting my job and then leaving because my work ethic and that has decreased. I think I'm better off leaving now when I still have that passion for it." (C1-4)

Organisational commitment
PSWs

"I'm having a lot of experience but in two and a half years, I learnt one thing, most of the people working in disability they are not happy with the system. Like especially they ... don't know exactly what is happening in the houses and they come and just show their bossiness and try to make changes, which are sometimes impossible. And another thing they are not happy with their pay scale, that also ... (commitment), then that person start thinking, 'Okay, I'm doing so much hard work and I'm not getting (rewarded)'." (C2-3)

Box 7.5: Respondent Views: Service Delivery
Lack of client-centred approaches
Managers

"...and then we look at that person-centred practice. So, what type of goals do they want to achieve? So very much focusing on the person holistically... I know [the CEO] spoke about the Boston model, which I'm not that aware of but I know it's there. But looking at those and seeing what other complimentary models exist for that person. And then, the third model, which I really have been a big advocate of, is the active service model." (M1-1)

Client

"I just want to walk." (CL1-1)

"...this is an industry in itself and these people are just taking advantage of everybody who can't understand. They don't stay the right number of hours, they just get you to sign for the hours that they're meant to be here but they don't stay. And I'm thinking, why should I pay for it...a three-hour shift, if they're only doing two hours around take me shopping..." (CL1-2)

Box 7.6: Respondent Views: Information for Clients

Fragmented information for clients

Client's Family (non- compensabl e sector)

"...no choices whatsoever. So luckily a speech pathologist had heard about a man that was doing good work at private rehab hospital in MelbourneHad nobody mentioned it to us we would've had to learn [how to look after our son] ..." (CF3-1)

"I did find [team of rehabilitative services] through a doctor In [name of hospital] they have one person, we were very close, she was in charge for the accidental there, she indirectly gave me a person's name to get in touch because her son got a similar situation." (CF2-1)

"I mean the family should investigate every possibility and we said to the doctor, 'Is it possible?' So they brought another person... Doctors should investigate.... Well we're doing the research; the family is doing the research. The doctors are not interested unfortunately, the specialists, ordinary GPs, I mean they should know that this person admitted nine times to a hospital for the same pain or the same symptoms, somebody has to say, 'What the hell is going with this girl.' ... And we couldn't get any support from any other doctors, except a couple..." (CF2-1)

"...there wasn't anything in [place name] for information, for support, for anything. So we just had to start from scratch. One of the things that we've always wanted to do ... is find a sort of a model where somebody, when you are in that position, like you said, in the hospital, where you can have somebody to walk beside you when you come home and you've got somebody beside you that not necessarily is going to annoy you or hassle you. ... but I've heard of people being discharged from the acute sector and you're virtually on your own... You haven't got that person that can walk beside you." (CF3-1)

PSWs

"Regular care plan reviews please. And when that comes around...So I guess regular reviews and meetings. At least every six months to a year ... One of my clients has cognitive abilities, that guy with the epilepsy, his cognitive ability has deteriorated terribly but he's the in the old people's home and they just get left there. And I find it increasingly more difficult to have a conversation with him and there have been no updates or anything. I did contact my coordinator and I said I was concerned about the amount he was eating and the amount he was going out and having the big meals and he's got diabetes. And I said, 'If I didn't mention anything I wouldn't feel comfortable if something happened.'" (C1-6)

Box 7.7: Respondent Views: Information Sharing

Poor coordination and information sharing

Managers

"Some people have very long-term relationships with us, e.g., 20 years relationship... care workers should be the 'canaries in the gold-mine', the care workers should be able to initiate actions and bring in specialist expertise. It is important to get them to report up correctly; we feel that if we can have early intervention, it is easier to provide service to the clients." (FG1-2)

"...for example, I picked up that we'd had a number of incidents in the car relating to one particular client. So myself, the support coordinator in services and some of TAC met to discuss this and their neuropsychologist as well and saying, 'Okay, this is everything we're getting.' I'm concerned that our staff members, like a couple of them have been targeted now, what do we need to do? Training them alone is not going to solve the problem because we need to get the neuropsychologist on board to sort of look at the support plan of the clients and whether that needs to be changed. Then we need to address the issue with our carers and then we needed to maybe look at the funding as well, so that's why we needed someone from the TAC there. Like can we get some of these shifts moved to like a two person shift and make a change in that sort of way as well. The difficulty is that doing all that, it's a very slow process, you're trying to get people on board. Like that's the thing, it takes like two to three weeks to get everyone around a table and then the result and actions take extra long." (M1-6)

Box 7.8: Respondent Views: Information Flows

Information bottlenecks

Managers

"... clarity of purpose with accuracy and completeness at the start point, to strengthen intake; to have a quality system based on accuracy of information at the start-point is key to building client relationship" (FG1-2)

"On the front-foot, they first needed to understand the needs of their clients correctly. Currently, the process and tools of introducing a system of diagnosing client needs accurately, needs improvement. Care-work on the back-foot therefore can be affected by this inaccuracy, as a single carer may work in multiple care organisations, carrying the risk of wrong client diagnostics without which their service delivery may be impacted." (FG1)

PSWs

"Often it is even a bit out dated and sometimes you get to a job and you might've been given the information but it's quite different to actually experience it first-hand." (C1-3)

"... But about their emotional situation you probably won't hear anything about whether like 'They're really independent so just be really careful.' ...I mean if they have got an actual mental health illness, like schizophrenia or anxiety or something like that, that's been diagnosed, you'd probably hear about it. But if it's more just about their personality and how they respond to things, you know, you're not likely to." (C1-3)

Box 7.9: Respondent Views: Information and Assistive Requirements

Issues about innovations and technology

Managers

"So see we don't use them well in [CP2], like iPads, for example. Why don't we use iPads, it's smarter to store documents. I know there's issue of security because in that... I'm not sure if you recall, it happened twice, once in Australia, once in Victoria. Once in Victoria there was a child protection worker who put everything to a USB stick and she got all the names of child protection children and it went missing." (M2-1)

PSWs

"We pretty much are to be liable for any misinformation or breakdown in communication. Because without that communication it's a key role of the care worker to make sure that any information is passed on." (C1-8)

Clients' Family (non-compensable sector)

"We're really, really interested in the assistive technology part in the future ... and where it can lead with [name of client] too with the assistive technology.... It's just trying to get [name of client] to the right level to be able to access any of it [technology]... I think the sky is the limit. I even saw a program on the TV about a lady they were doing this study in America. And it was so interesting; it was on brain waves, using brain waves to actually turn the TV on and to do stuff. So the sky's the limit. So [name of the father] and I always say that the best thing that we can do with [Name of their son] is keep him in the best physical position to be able to access this technology down the track. So the healthier and the better and the more we stimulate [name of their son] now, the better he's going to be able to tap into any of that that comes along. So I think we're really positive about all of that aren't we." (CF3-1)

Clients

".... And perhaps like an Island bench but a movable one with wheels so when you cook in the oven you can take that food out and put it on the... small trolley or island bench. Then from there you can lift it up to where you need it." (CL3-2)